

**THE PERCEPTIONS AND BELIEFS OF  
HEALTHCARE WORKERS ABOUT CLIENTS  
WITH TUBERCULOSIS**

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## Abstract

Tuberculosis (TB) continues to be a worldwide problem with one third of the world's population becoming infected, each year, with latent tuberculosis caused by *Mycobacterium tuberculosis*. From those infected, approximately nine million cases develop active disease resulting in two to three million deaths. An important factor for TB control is 'how' care is delivered to clients and that it is with thoughtful actions and effective communication. The literature revealed a paucity of qualitative TB research particularly related to healthcare workers attitudes and beliefs about TB clients in western countries. There was no literature found from New Zealand.

The study explored attitudes and beliefs of healthcare workers (HCW) towards clients with TB and the impact of these attitudes and beliefs on care. The beliefs of HCW relating to stigma associated with TB were also reviewed.

Six focus groups comprised of healthcare workers (doctors, nurses, clerical support staff and healthcare assistants), were interviewed in community and hospital settings. Following the analysis of the focus group data, ten individual 'face to face' interviews drawn from HCW from both settings took place. The general inductive method was used to analyse data.

The data collected from the study reflected the perceptions and beliefs of HCW, about what they felt TB clients experienced as opposed to their personal feelings about clients with TB. Healthcare workers reported that TB clients and their families suffer greatly from the impact of TB. These affects include emotional, psychological, physical, practical, social and economic factors. The observed level of impact of TB on clients depended on their identity, which was influenced by their cultural, and spiritual beliefs, their level of knowledge and the relationship they have with their HCW. Stigma associated with TB continues to be a worldwide problem and remains as much of an issue as it was hundreds of years ago. Stigma creates an added

burden for TB clients and can obstruct management of their illness and cause barriers to treatment and cure.

The research found that the healthcare workers interviewed, had positive attitudes, towards their TB clients and valued and enjoyed working alongside them. It is important that HCW working with TB clients have positive attitudes so that clients are able to accept their diagnosis and comply with their prescribed treatment. Negative attitudes can contribute to clients denying their disease, rejecting treatment and add to their feelings of stigmatisation and low self-esteem. The study identified that there were gaps in knowledge about TB, which contributed to HCW initially feeling fearful about caring for TB clients. With appropriate, timely education, knowledge can be increased; fear can be averted which will result in optimum care for TB clients and a positive experience for HCW.

The study was exploratory and further research is recommended. An ongoing in-service education programme would improve and enhance the Auckland TB control programme. The development and delivery of ongoing Community TB awareness programmes is paramount, in the quest to heighten awareness about TB, reduce stigma and promote wellness amongst the people of the Auckland Region.

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## List of Abbreviations

ACH	Auckland City Hospital
ADHB	Auckland District Health Board
AIDS	Acquired Immunodeficiency Syndrome
ARPHS	Auckland Regional Public Health Service
BCG	Bacille Calmette-Guerin
CDC	Communicable Disease Control
DHB	District Health Board
DOT	Directly Observed Therapy
EPISURV	Epidemiology Surveillance
ESR	Environmental Science and Research
FTE	Full Time Equivalent
GP	General Practitioner
HBM	Health Belief Model
HCW	Healthcare Workers
HIV	Human Immunodeficiency Virus
IC	Infection Control
JAM	Jill Alison Miller
LTBI	Latent Tuberculosis Infection
MDR TB	Multi Drug Resistant Tuberculosis
Mo	Medical officer
MoH	Medical officer of Health
MOH	Ministry of Health
MTB	Mycobacterium Tuberculosis

NZ	New Zealand
PHN	Public Health Nurse
PPE	Personal Protective Equipment
TA	Territorial Authority
TB	Tuberculosis
TBD	Tuberculosis Disease
USA	United States of America
WHO	World Health Organisation

# Chapter One: Introduction

This chapter includes the following: The purpose of the dissertation and rationale for its undertaking, background, personal involvement of the author and a general outline.

## ***Purpose***

To explore the underlying perceptions of healthcare workers in the Auckland region, about Tuberculosis (TB) disease and the influence these may have on healthcare delivery. The findings are needed to inform ongoing workforce development programmes, to heighten TB awareness and reduce potential stigma towards clients with TB. By ensuring staff have adequate knowledge about TB and positive beliefs about TB, they are more likely to deliver quality care to TB clients. Clients and families would benefit from improved care, receive positive TB education and feel able to follow and complete their drug regimen.

There were two specific objectives for this dissertation:

1. To explore the attitudes of healthcare workers (HCW) towards clients who have Tuberculosis disease (TBD)
2. To examine the beliefs of healthcare workers relating to the stigma associated with TBD

The Political Ecology of Tuberculosis in Auckland research study (described later in this chapter) is taking an extensive look at the qualitative aspects of TB treatment and care (The political ecology of TB in Auckland study, 2007). The project comprises five studies based in particular groups or categories of people and two historical studies. These have indicated that the outcome of treatment and the response of clients are greatly influenced by the care provider. A study exploring the attitudes and beliefs of health care workers therefore could reveal if ongoing staff development TB education programmes are necessary.

### ***Background about Tuberculosis***

Tuberculosis (TB) is a disease of considerable importance in New Zealand (NZ) and the world. TB is an airborne infectious disease, caused by infection of bacteria, called *Mycobacterium tuberculosis* (MTB). It is most commonly found in the lungs (70%) known as pulmonary TB or in any other part of the body (30%) referred to as extra-pulmonary TB (Heymann & Thuriaux, 2004). TB is spread person to person by droplet nuclei from people with pulmonary or respiratory TB during expiratory action such as coughing, sneezing or singing and inhaled by a susceptible contact (Heymann et al, 2004).

Globally it is estimated that one third of the population is infected with TB, and as a consequence, at risk of developing active disease. Each year, more than 8 million people develop disease and there are approximately 1.9 million deaths every year (World Health Organisation, 2006). Amongst these deaths, 90% occur in developing countries and disproportionately 75% occurs amongst the 15 - 54 age groups. This has a negative effect on the economy because this group contributes greatly to the workforce.

Since 1988, the annual number of TB cases in NZ has increased, with approximately 400 new notifications per year. The reason for this persistence is complex and includes migration from countries with high incidence of TB, social conditions and difficulties with making an early diagnosis (Turnbull, 2003).

Auckland has around half the number of cases of TB in NZ every year even though it does not have half the population. The median annual number of cases in Auckland between 1995 and 2004 was 184 cases annually. In 2004 TB rates were 15 per 100,000 in Auckland in comparison to 7.5 per 100,000 for the rest of the country (Auckland Regional Public Health, 2006).

There is a diverse ethnic population residing in the Auckland region with approximately 76 different ethnic groups identified. Each group has their own cultural beliefs, myths, stigma and information about TB. Stigma towards TB has an enormous influence on many ethnic groups and can hinder the

management and control of TB. There is a belief that the real issue of TB control is 'how' care is delivered and that much can be gained through working with TB clients by the 'thoughtful' application of care and communication (Porter & Ogden, 2002). In Auckland the healthcare workforce reflects the diverse ethnic composition of the Region. The HCW have their own cultural beliefs about health and illness and how these relate to TB disease.

### ***The increasing complexity of TB***

A previous study has indicated that migration of people with latent tuberculosis infection (LTBI) from high incidence countries is the prime reason for the persistence of TB in NZ (Das, Baker & Calder, 2006). This has resulted in the NZ Immigration Department introducing new Immigration requirements, whereby any person from a high incidence country intending to stay for six months or longer, is required to have a Chest X-ray (Johnston, 2005).

The emergence of multi drug resistant tuberculosis (MDR TB), (TB resistant to two or more commonly utilised anti tuberculosis drugs) has caused concern in the United States and the world (Centres for Disease Control and Prevention, 2006). Even more serious are recent reports of extensive drug resistant MDR TB isolates which are not only resistant to the main line anti - TB chemotherapy but have resistance to at least three of the second line medications (Thomas & Ellis-Pegler, 2006). Fortunately MDR TB is rare in NZ, with only nineteen cases recorded since National surveillance of drug resistance began in 1995. The cost of treating these cases is immense and has prompted the immigration department to develop more rigorous screening procedures and several multi drug resistant individuals have been deported (Park & Littleton, 2006).

Co-morbidities with Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) and TB have been blamed as the reason for the TB epidemic in Africa, Asia and the world. NZ has experienced relatively low rates of co-infection with only forty-five cases (1.2%) notified between the years 1995-2004 (Das et al, 2006). Although these rates have

remained low, vigilance and surveillance are essential to ensure they do not increase.

### ***Personal involvement***

I have been working as a Public Health Nurse (PHN) within the communicable disease control team (CDC) between 1994 and 2007, working alongside a multi disciplinary team of HCW involved with TB clients and their families. I have a role within the team as a TB liaison nurse, which involves networking, consulting and collaborating about TB issues.

The study was inspired by my involvement with members of the Political Ecology of TB study in Auckland, which is a multidisciplinary social science research project currently being undertaken by Dr. Julie Park, Dr. Judith Littleton and study team. The study explores TB from a framework that theorises 'the environment' as being partly the result of human interventions, which are themselves the outcome of political processes.

The study reported in this dissertation was undertaken within the Auckland region during 2006 - 2007, amongst the Auckland Regional Public Health (ARPHS) Communicable Disease Control team (CDC) and staff located at Auckland City Hospital (ACH) who work alongside TB clients. I was involved with the study design, preparation of the participant information sheet, consent form, focus group guidelines, ethics approval, conducted focus groups and individual interviews and data analysis.

### ***Dissertation outline***

The next chapter commences with a review of national and international literature, which is divided into three parts. Part one explores the epidemiology of TB both globally and within the Auckland Region. Part two, explores knowledge, attitudes and beliefs of HCW about TB/infectious diseases and the influence these attitudes may have on client's (with TB/infectious diseases) care. Part three examines stigma as an issue followed by Rosenstocks' health belief model. Finally the research methodology is reviewed, including focus groups and 'face to face' individual interviews.

Chapter three explores the research setting, including the context of the study, background, the community and hospital setting, the structure of the TB control programme in the Auckland region and the restraints experienced within the programme.

Chapter four outlines the methods utilised for this qualitative study. An overview of the focus groups, individual interviews, sampling frame and methods, data analysis and the application of the findings to the health belief model, is discussed.

Chapter five presents the results from the focus groups and individual interviews. The key categories, which emerged, are described and discussed. Further refinement of the categories, with a description of meaning along with excerpts found in the raw data to illustrate the meaning of the categories are presented.

Chapter six concludes the dissertation where issues arising are identified and methods to challenge attitudes and beliefs towards TB are discussed. Possible developments of TB educational/awareness programmes are examined in an effort to improve client outcomes. The summary and conclusion give a detailed summary of the findings from focus groups and individual questionnaires. The limitations of the study are addressed and the author will reflect on the study. Finally the possibilities of further directions and improvements for client outcomes will be explored.

## Chapter Two: Literature Review

The purpose of the literature review was to identify existing knowledge relating to the aims of the dissertation:

1. To explore the attitudes of Healthcare Workers (HCW) towards clients who have Tuberculosis (TB) disease.
2. To examine the beliefs of HCW relating to stigma associated with TB disease.

In this chapter the literature that was systematically reviewed will be presented. The following topics are explored and discussed:

- The literature review strategy
- Epidemiology of TB in the World, NZ and Auckland
- The knowledge, attitudes and beliefs of HCW and the influence of these on care
- Stigma and TB
- Health belief model
- The research methodology used for the research project
- Summary

### ***Literature Search Strategy***

Several Internet searches were undertaken to locate and review published articles available in English and available through the Auckland University Library. The literature was identified through systematic and extensive searches of bibliographic databases, specific government and organisational databases and specific hand searches of journals. The databases searched about HCW and beliefs included Medline and Cinahl using the key words **Healthcare worker** and **tuberculosis** and **perceptions** and **beliefs**. The search originally revealed 178,545 papers, which were refined by adding extra search words, and restricting papers to human and English print. Eventually 34 papers were selected and reviewed.

A literature search exploring the association between TB and stigma was mounted. A search was made in Medline and Google using the key words **Tuberculosis** and **stigma**. This revealed 86321 papers and after refining the search 28 articles were critiqued.

Background literature specific to tuberculosis control in the Auckland Region was accessed from Auckland Regional Public Health (ARPHS) central office located at Cornwall complex. This included TB Case and Contact protocols, 2003 National TB Control Guidelines and various policy and procedure documents.

Despite an extensive search no NZ studies researching the beliefs and attitudes of HCW were found. The overseas literature found related to TB compliance, but did not cover the impact negative attitudes of HCW caused for TB clients.

### ***Epidemiology of Tuberculosis***

TB is an airborne infectious disease caused by infection with bacteria called *Mycobacterium tuberculosis* (MTB). The most common form (70%) is found in the lungs and known as pulmonary tuberculosis. It can be found in any other part of the body (30%) and is referred to as extra-pulmonary TB (Heymann et al, 2004). Approximately one third of the world's population is infected with Latent TB Infection (LTBI) with about 9 million cases developing TB annually resulting in 2-3 million deaths. Most TB cases occur in the most populated countries of the world particularly in the developing world (World Health Organisation, 1998). The most challenging problem facing the world today is the emergence of MDRTB, defined as disease caused by *mycobacterium tuberculosis*, with resistance to at least Isoniazid and Rifampicin, two of the most effective anti tuberculosis drugs today. Multi drug resistance makes TB much more difficult to treat, where expensive second line drugs are required, twice a day and extends the drug regimen to 18-24 months (Palacios, Guerra, Illaro, Chalco, Sapag & Furin, 2003).

TB is spread from person to person by droplet nuclei from people with pulmonary or respiratory TB during expiratory efforts such as coughing, sneezing, talking or singing and inhaled by a susceptible contact (Heymann et al, 2004). The risk of transmission of the disease is greater for close contacts that have prolonged exposure to the TB case over time. This includes household members, work or institutional colleagues and close friends. People with compromised immune systems, exposed to TB, have a greater chance of developing TB than healthy people. The frequency of TB in some populations is increasing especially in communities with Human Immunodeficiency Virus (HIV) or Acquired Immunodeficiency Syndrome (AIDS) (Heymann et al, 2004).

The overall incidence of TB in NZ is low compared with most countries but has not declined over the last 20 years. TB remains one of the most notifiable diseases in NZ. The reason for this persistence is complex and includes migration from other countries with high incidence of TB, social vulnerability and difficulties associated with making an early diagnosis (Turnbull, 2003). Immigration has been an important factor that has contributed to the TB incidence in NZ. In 2001, 60% of all TB cases in NZ were born overseas (see Figure 1.1) (Turnbull, 2003). Rates of local transmission and reactivation are declining for NZ born populations, except for Maori and Pacific people, under 40 years old. Migrants and refugees are vigilantly screened and treated on arrival in NZ and although their incidence of TB remains high, TB is not generally spread in NZ. Refugees and migrants are therefore not an important source of TB for most NZ born populations (Das, Baker, Venugopal, McAllister, 2006).

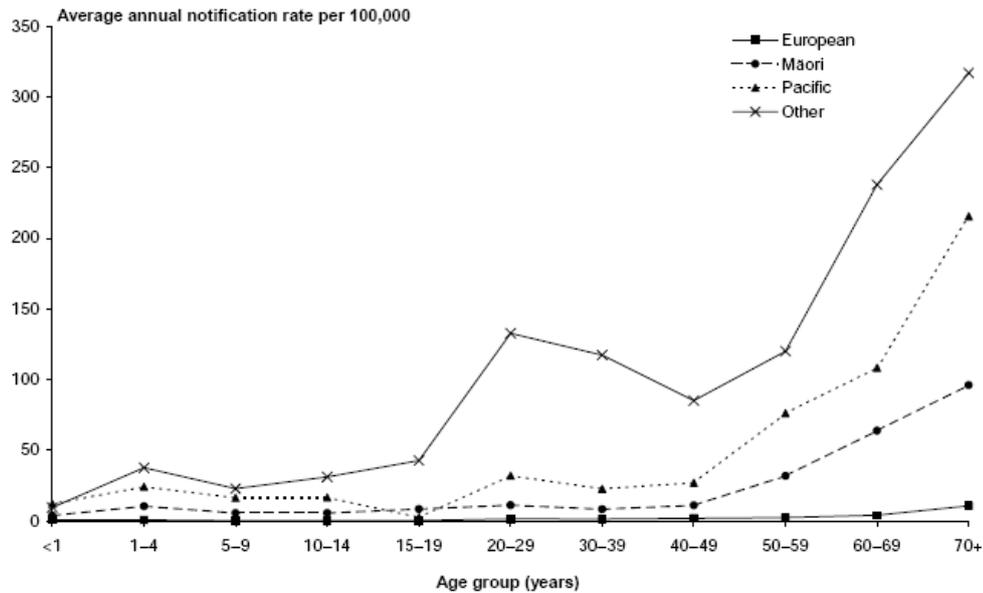


Figure 1.1 Tuberculosis notification rates by ethnicity, 1995-2001.  
(Turnbull, 2003, p.9).

The highest rates of disease are found in Central Auckland and South Auckland. These cases most commonly occur among people of non-European ethnicity, particularly Pacific and 'other'. In the NZ census 'other' relates to, Indian, Asian and people of African descent. In comparison to European, TB rates amongst Maori are five times greater; amongst Pacific people twelve times greater; and thirty five times greater amongst 'other' ethnic groups (Turnbull, 2003). TB affects the poorest and most vulnerable sectors, of the community the most, including migrants and refugees. In Auckland, notification rates amongst NZ born individuals of all ethnic origin are sixty times higher in the least affluent part of the Auckland region (Turnbull, 2003).

### ***The knowledge, attitudes and beliefs of Healthcare workers about Tuberculosis***

This literature review revealed many gaps in knowledge, about the attitudes and beliefs of HCW, about TB clients and the affect these have on care delivery. There was no NZ literature found about the specific attitudes and beliefs about HCW towards clients with TB. Overseas literature lamented the paucity of published qualitative literature on this topic (Dimitrova, Balbanova,

Atun, Drobniowski, Levicheva & Coker 2006, Mishra, Holme-Hanson, Sabroe & Kafle, 2006, Dick & Buskens, 2003). The literature that was available was primarily concerned with non-adherence to medication as opposed to specific HCW attitudes and improving the quality of care for clients. It is paramount when reviewing the literature to be aware of and reflect on the context of the research. Much of the literature found was drawn from developing countries where there was high incidence of TB, significantly more socio-economic problems and therefore had a different context to the TB control programme in Auckland.

HCW's knowledge, attitudes and perceptions about TB play an important role in their ability to diagnose and care for individuals with TB. A variety of factors, such as training, cultural and ethnic background, practice settings, preferred sources of information and learning styles influence them. The successful completion of TB treatment is influenced greatly by 'how' care is delivered to individuals. It is paramount that HCW supporting clients with TB have positive attitudes. This notion has been identified in the literature (Dimitova et al 2006, Porter et al, 2002, Messemer, Jones, Moore, Taggart, Parchmont, Holloman & Quintero, 1998). HCW caring for TB clients come from a wide range of backgrounds and perspectives. Personal and cultural factors may affect their practice. HCW need to be aware of and understand the impact culture can have on patients TB knowledge, attitudes and beliefs and practices. HCW should not try to challenge and destabilise cultural interpretations but should work with clients and seek constructive solutions (Edington, Sekatane, Goldstein, 2002).

### ***Risk factors for Tuberculosis***

In these studies, HCW from some work environments viewed TB as an infectious, dangerous and threatening condition. These features were associated with widespread negative perceptions of TB as a social disease arising from multiple socio-economic issues most prevalent in marginalised population groups. These included poverty, poor housing and living conditions, malnutrition, drug and alcohol use and unemployment (Dimitrova, et al 2006, Godfrey-Faussett, Kaunda, Kamanga, van Beers, van Cleef,

Kumwenda-Phiri & Tihon, 2002, Hawker, Bakhshi, Ali & Farrington, 1999, Johansson, Diwan, Huong & Ahlberg, 1999). In the Gambia, HCW expressed the view that TB was not only associated with poverty but also dirtiness and prostitution as well (Eastwood, 2002).

In contrast, people with TB from affluent backgrounds, were viewed differently. TB clients who came from more affluent social strata were perceived as disciplined and adherent to treatment while socially disadvantaged clients were labelled as unwilling to be treated and undisciplined (Dimitrova et al, 2006).

### ***Communication between care providers and Tuberculosis clients***

Communication between patients and providers is critical for effective healthcare. It is a fundamental element that helps to shape the patient provider relationship and foster trust. Communication includes using an appropriate level of language, use of interpreters, verbal and non-verbal expressions, cues and good listening skills by providers. Good communication reflects the dynamics of the relationship and can impact on trust, satisfaction and adherence (Tuberculosis Behavioural and Social Forum Proceedings, 2006).

A common theme cited as a reason for client non-compliance was poor communication, which sometimes resulted in a complete breakdown in the care relationship. HCW treatment of the TB client was influential in the treatment outcome (Dick, Lewin, Rose & Zwarenstein, 2004, Wares, Singh, Acharya & Dangi, 2003, Comolet, Rakotomalala & Rajaonairoa, 1998). Poor quality communication between HCW and patients was found to be the most significant factor associated with non-compliance (Mishra et al, 2006, Wares et al, 2003)

A study in Nepal amongst newly diagnosed Pulmonary Tuberculosis (PTB) clients in 1998 revealed that HCW exhibited dominant traits at times. They were described as responding aggressively to clients particularly if they

presented late to a pre-arranged appointment. Clients reported HCW shouting at them for minor incidents such as forgetting to bring their medication to clinic (Wares et al, 2003). In Nicaragua a further study conducted amongst clients, their families and HCW in 2003, reported that some HCW who were not accustomed to working with TB clients, displayed aggressive behaviour, shouted at the clients and eventually refused to work in the TB area (Macq, Solis, Martinez, Martiny & Dujardin, 2003). Many experienced professionals in South Africa have left TB services because of inadequate funding, resource and management issues. There have been reports of poor relationships between healthcare providers ranging from rudeness to abuse and neglect (Dick et al, 2004). The care delivered was described as rigid, task-oriented care and conversation with clients was at a very superficial level.

The communication between PTB clients and HCW was revealed to be poor, in the findings of a study amongst PTB cases in Nepal, between 1999 and 2001. The clients felt that they received inadequate explanations about their medications, the potential side effects and the length of the drug regimen. They believed that they were not listened to, taken seriously, or treated as having any integrity or being worthy of respect (Mishra et al, 2006). In a similar study some TB clients reported that they had good knowledge about their disease but had a lack of information about side effects and the consequence of non-completion of their regimen (Wares et al, 2003). Poor communication and negative attitudes were directly associated with non-compliance in Nepal, Bali and Manila (Mishra et al, 2006, Watkins, Rouse & Plant, 2004, Auer, Sarol, Tanner, Weiss, 2000). A further South American study also revealed that the communication skills of most HCW were poor (Jaramillo, 1998).

The information and education provided by the HCW and the subsequent relationship of the TB client and their provider is an essential component in the successful treatment of the disease (Moro, Desi, Lelli, Nicoli, Cajilloti & Falcone, 2005). Poor education of many people with TB is considered to be a fundamental problem contributing to the weakness of TB programmes (Watkins et al, 2004). The HCW has a pivotal role in providing accurate

information in a reassuring way and providing relevant knowledge to correct erroneous beliefs and current knowledge imparted (Liefoghe, Michiels, Habib, Moran, De Muynck, 1995). Accurate health educational efforts should not overstate or over dramatise TB, as this could reinforce stigma and denial (Auer et al, 2000).

In many instances HCW expressed the need for comprehensive, ongoing education programmes for themselves (Dimitrova et al, 2006, Mishra et al, 2006, Moro et al, 2005, Watkins et al, 2004, Messemer et al, 1998). Some reported feeling inadequately prepared for their role in TB control and that they had not received specific TB training. Participation in continuing education sessions was limited because of the opportunity cost of being absent from work (Watkins et al, 2004).

It is essential that programmes provide correct information and that the content is sufficiently explanatory and reassuring for staff to feel comfortable within the care setting. In some instances incorrect TB education may be delivered, such as HCW in the Gambia were found to have limited knowledge about the signs and symptoms of TB (Eastwood, 2002). It was reported that following an education programme to nurses about infection control in a HIV/TB setting in the United States of America (USA), their attitudes, became less positive because they perceived they were at risk. Increased knowledge did not correlate with more positive attitudes and decreased concerns. In addition attitudes are difficult to change and may require frequent training over a long time frame (Messemer et al, 1998).

### ***Relationships between care providers and Tuberculosis clients***

Good relationships between providers and clients form an important component of quality healthcare. Research suggests that interventions to promote patient centred care may result in greater client satisfaction and may be associated with improved health outcomes (Dick et al, 2004, Watkins et al, 2004).

There are diverse attitudes within HCW as was demonstrated where contrasting behaviour amongst HCW was reported. HCW that were working within the TB control programme were found to have positive attitudes. The research described a stark contrast in this behaviour with HCW working in the wider community in Nicaragua (Macq et al, 2003). The TB control staff exhibited empathy, compassion and care for the TB clients and expressed little fear of becoming infected. They were considered to be barrier breakers in facilitating relationships between their clients and HCW from outside the programme. The HCW working outside the TB programme were fearful of the TB clients and became oriented towards isolating all TB clients whether they were infectious or not. They tended to refuse to care for the TB clients or if absolutely necessary care was given with as limited contact as possible. They harboured deep mistrust for the TB clients and regarded them with suspicion. In addition to this reaction these HCW treated the TB programme HCW negatively. There was a transfer of the social stigma of TB to the HCW caring for TB clients. The HCW were viewed as being less qualified to others and comprising of a staff of nurse aides, nurses and rarely doctors. Their whole credibility compared with other HCW was questioned (Macq et al, 2003). At a workshop in Zambia it was also clear that staff were often not keen to work with TB patients, or in the TB corner, where directly observed therapy (DOT) and TB registration occurred (Godfrey-Faussett et al, 2002).

In a rural district of South Africa, HCW were cited as being disrespectful (Edington et al, 2002). This experience of bad treatment had influenced patients' decisions to not return for further care (Edington et al, 2002). The patients complained about inadequate explanations and the HCW lack of knowledge about their own cultural interpretations. Some clients reported feeling fearful of the health team and in particular being rebuked by the doctor. It was found that doctors made themselves available to patients in areas they felt most comfortable but as regards availability, information and motivation issues, where effectiveness has been proven, they did not perform well and even less well with non-adherent patients (Comolet et al, 1998).

## ***Stigma and Tuberculosis***

Evidence both in research and practice, shows that stigma associated with TB is universal. The consequences of stigma can be seen affecting care-seeking behaviours, as people have been known to hide their TB status to family or friends, out of fear of being ostracized. Research demonstrates that in some cases personal rejection occurs as a result of strong stigma surrounding TB. (Tuberculosis Behavioural and Social Forum Proceedings, 2006).

The term stigma was derived from ancient Greek times when attention was attracted to the immoral behaviour of slaves, convicts or traitors by branding them with an external mark to illustrate their spoilt status (Searle, 2004). Historically, infectious diseases including TB have been accompanied with stigma from individuals and communities throughout the world. Most literature about stigma has been based on the research and work of sociologist Erving Goffman (Goffman, 1963). His theory suggests, the effect of stigma on an individual excludes them from being socially accepted leading to a feeling of unworthiness, internally and externally, rendering them 'reduced in our minds from a whole and usual person to a tainted and discounted one' (Goffman, 1963 p.12). Goffman describes a stigmatised person as being discredited and made to feel less than human. Goffman classifies people who exhibit regular behaviour as 'normals'. These 'normals' discriminate against stigmatised people preventing them from leading full and happy lives.

When stigma is examined within a broader context, power and domination relationships are revealed and the methods in which dominant groups maintain control are demonstrated. There are political, economic, cultural and social influences that underpin stigma. This can be demonstrated by this following definition of stigma as described by Scheper-Hughes

*Stigma is a discourse, a language of human relationships that relates self to other, normal to abnormal, healthy to sick, strong to weak. It involves those exclusionary, dichotomous contradictions that allow us to draw safe boundaries around the acceptable, the permissible, the desirable, so as to contain our own fears and phobias about sickness, death and decay*

*madness and violence, sexuality and chaos. The tactics of separation allow us to say that this person is 'gente', one of us, and that person is 'other' (Scheper-Hughes, 1992 p. 374).*

A further recent definition of stigma describes it as a social process, worsening already existing inequalities and exclusions (Parker & Aggleton, 2003). When the focus is shifted from the personal psychological and behavioural analysis of stigma to social processes it allows the possibility of overcoming stigma and reducing the associated discrimination (Parker et al, 2003).

Social stigma is recognised as an important barrier for successful care of clients with TB. TB has been considered as a 'dirty disease' 'a death sentence' or as effecting 'unclean' people (Johansson, Long, Diwan & Winkvst, 2000). Two types of stigma have been identified in association with TB, enacted stigma and perceived stigma. Enacted stigma relates to discrimination due to social inferiority, while perceived or internalised stigma is a feeling of inferiority as a result of the fear of enacted stigma. This can be demonstrated from TB clients refusing to disclose their diagnosis to others or feeling ashamed of having TB (Eastwood & Hill, 2004). Stigma associated with TB is frequently associated with diagnostic delay and poor or non-compliance creating negative impact on TB control. It can also be as a result of existing beliefs about the cause of TB or the severity of the illness (Watkins et al, 2004). The literature about stigma associated with the emotional and social distress of TB clients is sparse (Eastwood et al, 2004, Auer et al, 2000).

The cause of stigma associated with TB can be as a result of misinformation about TB transmission, HCW attitude (Auer et al, 2000) or health care organisation. Stigma also was described as closely related to factors such as gender roles, socio economic status and level of education and seemed to result in concealment, resulting in delayed diagnosis (Johansson et al, 2000). It may also be a result of other existing client characteristics that are sources of discrimination such as ethnic group, and co-infection with HIV (Macq, Solis

& Martinez, 2006). Stigma has often been associated with the dual diagnosis of HIV/TB in parts of Africa (Heymann et al, 2004).

The stigma of TB is powerful because the public fear infectious diseases. Lack of knowledge about TB fuels fear and many people continue to be oblivious that TB is curable. Often cancer is more socially acceptable to some groups of people. TB clients often endure more than physical symptoms and suffer from emotional distress because of stigma imposed by society, rejection by friends and family. This rejection and shame often prevents people seeking treatment and completing treatment once it has been commenced (WHO Report, 1998). Uncertainties about the fact that TB is curable prevail widely and contribute to the social stigmatisation of TB clients (Liefoghe et al, 1995). One study concluded that the predominant affects experienced by TB clients included stigma, social rejection and personal threat (Westaway & Wolarans, 2004). Further research undertaken in the Gambia described how clients believed people gossiped about them. They assumed that people were reluctant to share things with them and avoided them. Sometimes TB clients became homeless after their landlord discovered their diagnosis and evicted them (Eastwood, 2002). Negative behaviour can result in further isolation of TB clients due to incorrect beliefs that TB is transmitted through eating utensils and sexual behaviour. The prevalence of stigma is greater in rural areas (Harper, Ahamadu, Ogden, McAdam & Leinhardt, 2002).

In summary the five following findings were evident in the literature reviewed.

- TB is a highly stigmatised disease which has been around for many years
- There are two types of stigma, enacted stigma and perceived stigma
- Stigma about TB can be directly attributed to by misinformation, myths, old beliefs or ignorance
- Stigma can contribute to TB clients concealing their status, avoiding or not completing their treatment regimens
- TB clients frequently encounter stigma from family, friends, communities and HCW

### ***Health Belief Model***

For the purpose of this research the Health Belief Model (HBM) was chosen as a framework. This is a theoretical model, which originated from the discipline of social psychology, to identify the determinants of behaviour change. It attempts to explain and predict behaviour by focusing on individuals' attitudes and beliefs. The HBM was originally developed in the 1950s by sociologists Hochbaum, Rosenstock and Kegels working in public health in the USA. The model was developed in response to the failure of a free TB screening programme (Glanz, Rimer & Lewis (2002).

This model may contribute to understanding how clients make decisions about accepting their TB diagnosis and complying with drug regimens. The HBM, highlights the function of beliefs and decision making, was originally described by Rosenstock (1966) and modified by Becker (1978), with its primary use being prediction of protective behaviour. The model suggests that whether or not clients change their behaviours, will be influenced by an evaluation of feasibility and its benefits weighed against cost (Naidoo & Wills, 2000).

The themes revealed from data analysis of the focus groups and 'face to face' interviews are all a rich matrix of the TB experiences of clients as described by HCW. These fit well with the different parts of the HBM. All the identified categories in the research interrelate and are independent and this also holds true of the HBM. In order to simplify this I have taken examples of the research and discussed linkages with the various aspects of the HBM in Chapter Five.

Health beliefs concern perceived severity of the disease; expectations towards treatment and cure; health motivation; benefits of drug regimens; and the perceived advantage of continuing treatment given competing events such as geographical, economical, accessibility of drugs and predisposition (see Figure 2.2).

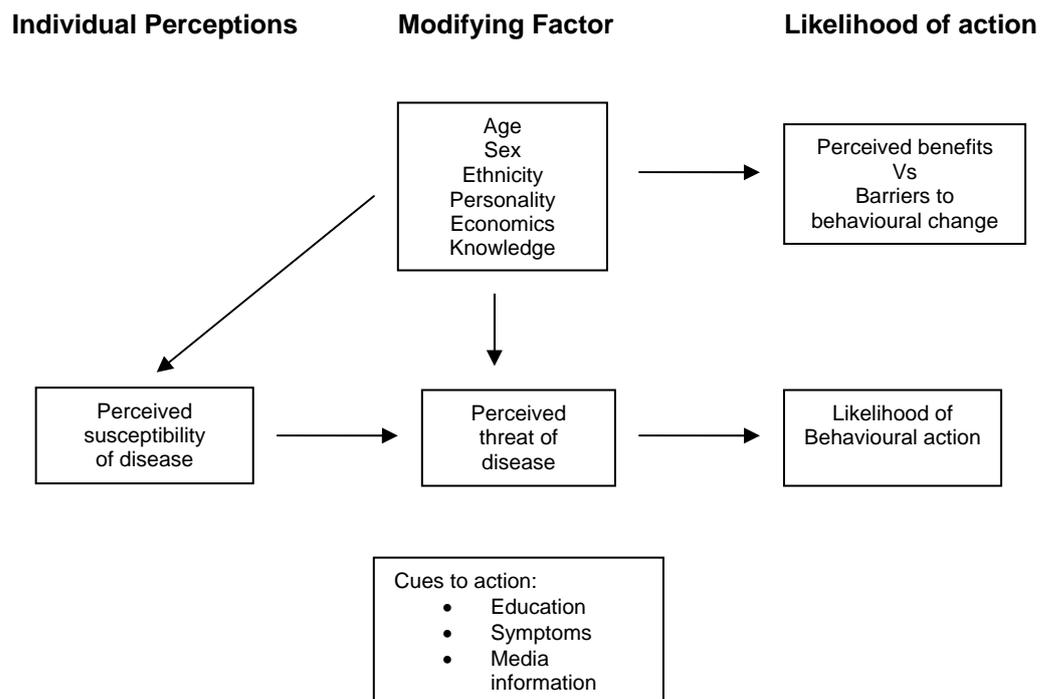


Figure 2.2. The variables of the Health Belief model.  
(Glanz et al 2002, p.52.)

It is important that HCW know and understand their own HBM, in order to deliver culturally sensitive care, they need to know the role of cultural beliefs in guiding a client's health practice and response to illness episodes (Anderson & McFarlane, 2000). Health behaviour is influenced by perceptions of a health threat as well as aimed at the value associated with taking preventative actions (Becker, 1978). It attempts to model decision making (whether to comply with medical treatment or not) taking in to consideration influencing factors: readiness to be adherent, motivation to comply and enabling issues. Assumed influences include motivations e.g. clients acceptance of TB and the understanding that untreated TB is serious and the belief that drug regimens are effective and will cure TB. Issues that are concerned with continuing motivation and enabling factors include geographical location of therapy, cost, side effects of medication, relationships with HCW and stigma surrounding TB (Stainton-Rogers, 1991).

Although the model has received considerable criticism for being too simplistic and individualised (Stainton-Rogers, 1991) it fits well when examining TB and HCW attitudes and beliefs. It is suggested that the theory oversimplifies the complexity of the interwoven articulated arguments given by clients with TB (Stainton-Rogers, 1991).

The HBM principles were helpful to the research and provided a framework for a model developed from the findings. Many believe that behaviour change for HCW and clients with TB remains a challenge for health promotion within TB control programmes. Effective education programmes relate to how clients and their HCW make decisions and manage compliance throughout their TB journey. Extensive staff education and community programmes to reduce stigma and heighten awareness about TB must also accompany these to enable clients to make supportive choices.

### ***Research Methodology***

There were no previous studies found in the literature search exploring HCW attitudes and beliefs about TB clients in NZ therefore the project is exploratory. Qualitative research methods are especially useful with exploratory studies because they provide the opportunity to collect a large amount of data from a few participants about their experiences related to certain phenomena (Thomas & Hodges, 2005). Qualitative research was very appropriate in this study because it gave emphasis to meanings, experiences and participants views (Pope & Mays, 1995). It answered the questions related to human attitudes and behaviours. Knowing HCW knowledge, attitudes and beliefs will enable future planning of education programmes both in the hospital and community settings.

The qualitative approach used in this research is different to quantitative descriptive studies where the researchers pre-select variables to be studied. From the results of quantitative descriptive studies conclusions are reached, by using statistical tests, which are based on a set of assumptions (Sandlewski, 2000).

The following specific methods are reviewed as they were used for the research

- Focus groups using open ended questions
- Individual 'face to face' interviews using semi-structured interviews with open ended questions

### ***Focus Groups***

A focus group discussion is a qualitative research method, which has been advocated, increasingly in medical research (Liefoghe et al, 1995). A focus group is a 'group interview' centred on a specific topic and facilitated by the researcher (Baum, 1999). They are informal sessions in which participants are asked their perceptions on a particular topic. Focus groups are specifically designed to yield information on beliefs, values and understandings of issues (Liefoghe et al, 1995). The method consists of a dialogue that is accepting, inviting and facilitating. Focus group methodology was an appropriate method to examine the beliefs and perceptions of HCW about clients with TB.

The data from focus groups has been described by Baum (1999) as an effective approach to exploring knowledge and experiences in order to enhance understanding of the phenomena. Focus groups are cost effective, time efficient, quick to conduct and provide rich in-depth information from a greater number of participants at one time (Marshall & Rossman, 1999). Focus groups encourage participation from those who may be reluctant to be interviewed individually (Kitinger, 1995). They also give people who feel they have nothing valuable to contribute an opportunity to participate in research. However focus groups may discourage members from discussion if they feel their opinion is different from the majority in the group. The researcher has less control over data collection from focus groups than when using 'face to face' interviews (Kitinger, 1995). The researcher addressed this problem by presenting participants with guidelines as described by Krueger (1994), to each focus group, and strictly adhering to them (see Appendix 3).

### ***Individual 'Face to Face' interviews***

The most common type of interviewing is individual 'face to face' verbal interchange. Interviewing can be structured, semi structured or unstructured (Denzin & Lincoln, 1994). Semi-structured interviews are used widely in qualitative research to understand the reasons why people behave in particular ways, by exploring informants' perceptions, attitudes and experiences (Harvey-Jordan & Long, 2001). Semi structured interviews allow respondents to answer questions in their own words which is a reflection of their thoughts (Kitchin & Tate, 2000). These interviews employ a series of open-ended questions based on the topic areas the researcher wants to cover and provide opportunities for various themes to emerge (Harvey-Jordan et al, 2001). It can include opportunities for clarification and discussion that are usually excluded from survey research or structured interview techniques. Open-ended questions are appropriate and powerful under conditions that require probing attitude and gleaning information that is interlocked in a social structure or personality (Miller, 1978).

The data collected is likely to be more accurate because the interviewer is able to repeat and explain the questions, which can clarify the meaning of answers. The interviewer has more control over the interviews as they can guide questions and end answers that are too voluminous or have gone in the wrong direction. The language of the survey is able to be adapted to the ability or education level of the person interviewed. This was especially applicable to the research undertaken because the respondents were drawn from a wide variety of professional groups. Sensitive questions can be asked with care and by observing the informants response the subject can either be changed or further explained in an alternative way (Miller, 1978). Paton (1987) highlights a weakness of semi-structured interviews, in that important topics may be omitted from the prompt schedule. 'Face to face' interviews can be time consuming and more expensive to conduct than alternative survey methods (Miller, 1978).

## **Summary**

This chapter has reviewed the current literature relevant to the research project being undertaken. The significance of TBD and the attitudes and beliefs of HCW about clients with TB has been explored. The issue of stigma associated with TB has been examined, as has a HBM. The research methods have been critiqued including a glimpse at qualitative methods, focus group interviews and individual 'face to face' interviews.

Six key findings from the literature review were:

- TB remains a problem in the World, NZ and Auckland. Although NZ does not have high incidence rates of TB there are still issues surrounding TB clients and their families
- HCW attitudes and beliefs about TB can greatly influence the experience of a TB client and extended family. Positive relationships are important components of successful TB control programmes
- Ongoing, appropriate TB health education is essential for clients, families, communities and HCW
- Stigma is a major barrier to TB and other infectious diseases preventing timely investigation, treatment and cure
- The HBM is an appropriate theoretical framework to support this research and fits well with the themes identified from the data analysis
- Qualitative methods were an appropriate method to use for this exploratory research project

In Chapter Three the research is placed within the context of Auckland, NZ, including the epidemiology related to TB in NZ and within the Auckland Tuberculosis Control Team.

## Chapter Three: Research Context

This chapter describes the context of the research including a brief outline of the New Zealand Health system, the Auckland Region, Auckland Regional Public Health Services (ARPHS) and Auckland City Hospital (ACH). The structure of the Auckland Tuberculosis Control Programme is discussed along with constraints experienced by the programme.

The population of NZ is approximately 4.1 million, of whom 78% are of European descent. Maori, who are the indigenous people of the country, comprise 14.9% for part Maori and 7.9% for full Maori. There has been an increase in migrants of Asian ethnicity who now comprise 6.6% of the population and who have overtaken the Pacific Island population of 6.5% people. NZ has a relatively open immigration policy and 20% of the population were born overseas. Immigrants are drawn from many nations and there are increasing numbers from East Asia including Chinese, Japanese and Korean people. There are also numerous migrants from South East Asia including Indian people (Statistics New Zealand, 2004).

The Auckland region is the largest urban area within NZ. This region is the most ethnically and socially diverse group contained within the country. These factors create enormous challenges for health maintenance and achieving health gain in the future. The region consists of seven Territorial authorities (TA's): Rodney District (estimated population 89,100 on June 30<sup>th</sup> 2005), North Shore City (212,000), Waitakere City (191,000), Auckland City (425,000), Manukau City (332,000), Papakura District (43,700), Franklin District (57,400). The Region has a younger population, generally, than other NZ regions (Auckland Regional Public Health Report, 2006).

### ***New Zealand Health System***

The NZ health system comprises of public, private and voluntary sectors, which combine to provide and fund healthcare. Seventy eight per cent of health care is publicly funded with out of pocket payments and private insurance providing the rest of the funds (Statistics New Zealand, 2004).

The Ministry of Health (MOH) primarily advises government about health policy and disability support and is responsible for monitoring the performance of District Health Boards (DHB) and other crown entities. The Ministry implements, administers and enforces relevant regulations and legislation, provides health information and processes payments. It provides national planning and guidelines, maintains service frameworks and plans and funds public health, disability support services and other centrally located services (Statistics New Zealand, 2004).

Public health services are generally provided to populations as opposed to individuals. Public health supports a population health approach that considers all factors that determine health and systematically plans to address each component while trying to reduce inequalities of health.

The Public Health Directorate of the MOH provides policy and strategic advice on public health issues and services, monitors the health status of the population, develops and enforces public health legislation, develops public health strategies and plans and funds public health services.

There are twelve public health units based in DHBs that provide health promotion, health protection and disease prevention services to all of the 21 DHB districts (Statistics New Zealand, 2004).

Medical practitioners are required under the Health Act 1956 to notify their Medical Officer of Health (MoH) of cases of notifiable diseases they encounter. Notification data is recorded on a computerised database in each public health service and is paramount in guiding local control measures. The data is subsequently collated and analysed at a national level by the Institute

of Environmental Science and Research (ESR) for the MOH (Statistics New Zealand, 2004). The MOH monitors the prevalence of communicable disease, coordinates national response to outbreaks and is responsible for the immunisation schedule and control of communicable disease through designated medical officers of health (Statistics New Zealand, 2004).

### ***Tuberculosis in New Zealand***

TB is a disease of considerable importance in NZ and the world. The number of TB cases has increased in recent years. The overall incidence rate of TB in NZ is low compared with the world but has not reduced over the last 20 years (Ministry of Health, 2006). The rates are slightly lower than in the United Kingdom (12 per 100,000) but higher than Australia, Canada and United States of America (5-6 per 100,000). The reason for this persistence is complex and includes migration from countries with high incidence of TB and social conditions that favour transmission (Das et al, 2006).

Auckland reports approximately 200 cases of tuberculosis annually, which is half the total of NZ cases. The highest rates of disease are shown in Central Auckland 23.0 per 100,000 and South Auckland 19.0 per 100,000. These are both urban areas with a high population of migrants. Ethnic disparities have increased in recent years amongst individuals of non-European ethnicity, particularly Pacific and people of Asian, African and Indian decent described in the NZ census as 'other' ethnicity. In comparison to European, TB rates amongst Maori are five times greater; amongst Pacific people twelve times greater; and thirty five times greater amongst 'other' ethnic groups (Turnbull, 2003). TB affects the poorest and most vulnerable sectors of the community the most. In Auckland, notification rates amongst NZ born individuals of all ethnic origin are sixty times higher in the least affluent part of the region (Turnbull, 2003).

### ***Auckland Regional Public Health Service***

Auckland Regional Public Health Service (ARPHS) is a regional public health service provider that aims to improve and protect the health of the people within the region. ARPHS has an obligation to work alongside central and

local government, health service providers, iwi and communities to plan and develop effective strategies that protect and promote health of the people.

The approach taken is a whole of the population approach, however targets resources to areas with the greatest health need. The service has an outcomes focussed framework, which acknowledges that effective public health, is only achieved in partnership with the whole of the community (Auckland Regional Public Health Service Report, 2006).

The major public health role of ARPHS in TB control is to prevent spread of the disease. This is achieved by following six principles:

1. TB surveillance

ARPHS has a very robust reporting system where notifications are received by a TB clerical support person and processed onto a national database called Episerv. This allows the collection of specific data about TB cases and ensures that possible linked outbreaks are notified early. All positive TB Laboratory specimens are also notified in this way ensuring the notification of TB cases can not be accidentally omitted.

2. TB case management:

This process ensures that clients diagnosed with TB are supervised enabling them to complete their prescribed drug regimen. The regimen involves taking medication for a minimum of six months and can extend to a period of several years.

3. Contact tracing:

The contacts of infectious cases are followed up and investigated for possible infection.

4. Treatment of Latent Tuberculosis infection (LTBI):

Contacts found to have infection are assessed for relevant risk and may be offered a six-month course of prophylactic antibiotics. These clients are then offered supervision to ensure successful completion of their course

(Auckland Regional Public Health service Report, 2006).

5. *Bacillus Camillite Guerillan (BCG) Immunisation:*

A vaccination service operates throughout the region to offer protection to infants from specific high-risk groups. The programme has an in-hospital programme at Middlemore hospital and offers community vaccination from sixteen different clinic venues.

6. *Community TB awareness programmes*

Education sessions are delivered to a variety of different communities within the region. These awareness projects seek to give accurate information about TB, dispel myths, misinformation and reduce stigma. Sessions are delivered to a variety of different groups including healthcare students, various health organisations, community care organisations, and ethnic communities.

***Communicable Disease Control Team***

ARPHS has a dedicated communicable disease control team (CDC) that is responsible for the follow up and care of individuals and populations with communicable diseases. Approximately 85% of the workload is dedicated to TB cases and their contacts. The team consists of a multi disciplinary team that works together in an effort to provide optimum outcomes for their clients.

There are 15 PHNs, five Health Assistants, two Medical Officers, two Clerical Support Staff and three MoHs. In addition to this generic team a BCG vaccination team of four nurse vaccinators and three clerical staff provide support. The ethnic composition of this group is diverse with a high proportion of the staff identifying as European. The team operates during normal working hours five days a week and in addition provides a weekend service which is delivered by on call staff and funded as over time.

***Auckland City Hospital***

Since October 2003, Auckland has a new acute adult hospital on the Auckland District Health Board's (ADHB) Grafton road site. It merges the

services of Auckland, Greenlane and National Women's hospitals into one building and is linked to the Starship Children's Hospital. This represented a fundamental reorganisation for the staff working at ADHB.

The new Auckland City Hospital opened in 2003 is nine levels high, which is five levels higher than the existing hospital building. At around 80,000 square metres the building is one of the largest public buildings in NZ (Auckland District Health Board, 2007).

There are two main wards within the hospital that care for TB clients. One ward admits the more infectious smear positive cases. These clients often require containment isolation until they are deemed non-infectious. The ward is a 24-bed acute respiratory service accessing patients from throughout NZ and the South Pacific. This unit is unique in Australasia because there is ongoing ventilation occurring on the ward, whereas ventilation is usually restricted to an intensive care facility. Clients include individuals with cystic fibrosis, lung transplants, pulmonary hypertension and a mixture of respiratory clients requiring non-invasive ventilation post lung transplant to complicated respiratory disease. Some patients require protective isolation as opposed to others who need containment isolation in negative pressure rooms. Those requiring containment isolation include clients with infectious communicable diseases, mainly TB. The ward has six negative pressure rooms with the potential to develop a further two rooms should the need arise.

The clients are drawn from multiple ethnic groups, with a high proportion of them identifying as Maori, Pacific or Asian ethnicity. There is a high rate of bronchiectatic disease in the ward. The ward population tends to be derived from a lower socio-economic group and in addition many clients present late after delayed diagnosis and subsequently receive treatment late. This results in a severely ill group of clients.

The TB clients can be in this unit for some time, ranging from a few days to several months and their condition can range from seriously ill to fit and well.

Contrary to this status the other clients in the ward tend to be of high dependency status and require intensive nursing and medical care.

In 2006 there were 32.4 full time equivalent (FTE) Registered Nurses who collectively cover a 24-hour, seven days a week service. There are three medical teams based in the ward. Each team consists of resident medical officers, including a house surgeon, registrar and consultant. There are two clerical support staff and no health assistants. The staff is a multi-ethnic group and reflects the client group they care for.

The other ward at the hospital that accepts TB clients is an infectious disease unit. The TB clients tend to be extra pulmonary or smear negative cases and do not require containment isolation in a negative pressure room. This ward is a 24-bed acute infectious disease ward that, at times, accepts the Medical wards overflow patients. The staff numbers of the unit are similar to the team described above.

### ***Auckland Tuberculosis Control Programme***

This programme is a joint programme between hospital and community that is guided by National Guidelines and Regional protocols. The programme includes treatment supervision, contact tracing and treatment of contacts with LTBI and an immunisation service for at risk infants and eligible TB contacts. All TB clients are jointly case managed between the two services that aim to provide an optimum seamless service for TB clients. Protocols have been developed in partnership and are used across the services in the region.

There is excellent communication and collaboration between the teams and regular formal monthly Regional meetings operate to discuss mutual issues and facilitate change. At these meetings there are attendees representing the four hospitals within the region and key personnel from ARPHS.

The MoH has powers under the Tuberculosis Act 1948 to ensure clients suspected of having TB accept investigation and treatment services. This means that TB clients who refuse treatment can be incarcerated until deemed

not a public risk. Should the person be unable to pay for treatment there is provision under section 9 and 10 for the MoH to issue an order requiring the person to undergo the necessary investigations or treatment without incurring cost to themselves (Pikolz, 2007).

In effect, all investigations and treatment of TB in NZ is free for all TB clients, if under a compulsion order. Unfortunately, the finance department of the hospitals have become aware of this situation and often this free treatment can have a negative influence, on residency status at a later date. The involvement of the finance departments within the DHB with section 9 & 10 letters, coupled with the change in immigration policy has created adverse issues for TB clients and the HCW caring for them. In some circumstances, details of some clients not eligible for free TB care because of their residency status has been forwarded to immigration from the hospital finance department. This has resulted in immigration deporting some TB clients and other TB clients have gone into hiding.

### ***Limitations of the control programme***

The control programme has been in place since 1994 and in the author's view is a robust programme with few problems. There are some limitations, including no jurisdiction over the private sector. Some respiratory physicians manage very few TB clients and therefore the management is not always optimum. The drug regimens are frequently incorrectly prescribed and instructions given to the client to take the medication are not always accurate. Clients are notified to the Public Health Service and a PHN covering the geographical area the client resides in is assigned to the supervision of the case. This may provoke initial resentment because of the competing interests between private and public services. These problems are not insurmountable and are often mutually solved.

There are some TB clients who visit or migrate to NZ who are already diagnosed with TB. They frequently have in their possession medication prescribed to them from their country of origin. They may also attempt to receive further supplies by having medication mailed to NZ or carried in by

relatives or friends. Other immigrant TB cases are suspicious of the TB 'western' care delivered in NZ and prefer the drug regimens prescribed from their home country. These individuals may avoid input from the TB control services and refuse to comply with standard treatment.

Often the TB control programme receives information from General Practitioners (GP) and there have been occasions when medication has been intercepted by customs either at the ports or at mail centres. The programme seeks to supervise the medication of people with TB, ensure compliance and reduces the possibility of the development of drug resistance. This avoids the public health risk of the transmission and spread of TB.

### ***Migrant health screening***

In 2004 the Immigration Minister Lianne Dalziel announced in a media statement that a new immigration health and disability-screening programme would be phased in. The changes reflected the international environment where numbers of foreign students to Western countries were increasing. The move was an effort to ensure that publicly funded healthcare systems were not affected adversely and utilised by foreign-born nationals. The change was that people from countries with high incidence rates of TB, entering NZ for six months or more, would be required to undergo TB screening off shore before arriving in NZ (Johnston, 2005).

This change in policy resulted in many negative responses, some from politicians, some in the media and some within the health sector. A number of TB clients particularly those with complex, multi drug resistant organisms were deported. In the mid-2005 a Korean visitor was deported amidst much publicity and negativity from politicians, media and the general public, stirring up racial hatred and fuelling the belief that TB was exclusively a disease acquired from overseas countries. One article in the NZ Herald reinforced this notion and suggested that the solution was immigrants should be turned away at the border (Johnston M, 2005). These factors all compound issues surrounding stigma and make TB control in NZ difficult for all parties concerned.

The result of this negative reaction on many TB clients or their contacts was the fear that they would also be deported and that TB investigations and treatment were no longer free. Over the last three years some people have gone into hiding and avoided seeking medical care because of their extreme fear. Sadly with the above policy changes clients that were issued with Section 9 or 10 letters have experienced problems with their immigration status or have had extensions to their visas denied.

### ***Summary***

This chapter has discussed the context of the research within the TB control programme in the Auckland region, NZ. The significance of TB in Auckland has been briefly outlined. Chapter Four will describe the Methods utilised in the research project.

## Chapter Four: Methods

This chapter outlines the methods of the qualitative study. An overview of focus group research; 'face to face' interviews; sampling frame and methods; analysis and results of the data from the study will be discussed.

### ***Purpose of Study***

The purpose of the study was to explore the underlying perceptions of HCW about TB disease and the influence these may have on healthcare delivery. Preliminary findings indicated a need to implement ongoing workforce development programme, to heighten TB awareness and reduce potential stigma, towards clients with TB. Staff would gain increased knowledge and positive beliefs about TB, ensuring that they deliver quality care to TB clients. Clients and families will benefit from this improved care, receive positive TB education and feel able to follow and complete their drug regimen.

### ***Objectives***

There were two objectives of the research.

1. To explore the attitudes of HCW towards clients who have TB disease.
2. To examine the beliefs of HCW relating to the stigma associated with TBD.

This study utilised a wholly qualitative methodology to explore HCW's beliefs and attitudes about TB and to investigate possible strategies to improve client care delivery. Focus Group interviews amongst healthcare assistants, clerical support staff, nurses and doctors working alongside TB clients either in the community or hospital setting in the Auckland Region were undertaken. The data from these groups was analysed, themes and sub themes were identified. This process assisted the development and refinement of the interview schedule. This schedule was used with 'face to face' interviews where the researcher was able to probe HCW's attitudes and beliefs in more depth. This study was approved by the Northern Y Ethics committee in Hamilton on April 16<sup>th</sup>, 2006.

### ***Focus Groups***

Six focus groups were conducted in total, four in the community and two at ACH. The sampling frame of the study was multi-disciplinary HCW consisting of health care assistants, clerical support staff, nurses and doctors who work alongside TB clients, either at ACH or from ARPHS.

Purposeful sampling was employed to select the volunteer participants for the six focus groups. A personal invitation by letter and Participant Information Sheet (see Appendix 1) was given to each eligible health care worker that fitted within the sample frame. The sample was stratified by: hospital or community multi-disciplinary staff who worked alongside TB clients. Participants were selected from different occupations and focus groups were conducted amongst these specific disciplines.

The six focus groups were conducted amongst specific occupations to minimise potential domination of some members and reduce inhibition of expression in others. All focus groups were conducted by the researcher (JAM). A pilot focus group was conducted amongst nurses to ensure the validity of the focus group questions. Interviews were arranged at work sites during work time, making it convenient for participants to attend. The same questions were used with each group and provided a flexible guide to channel questions (see Appendix 3).

A letter explaining the purpose of the study and an invitation to participate was sent to all eligible participants at their work site, by a clerical support person. Interested participants contacted the clinical nurse specialist of the area and a further invitation with a participant information sheet, date, time and venue of the scheduled focus group was returned to them.

The focus group process was designed around guidelines by Krueger (1994). Participants were welcomed and encouraged to feel comfortable and relaxed. Light refreshments were supplied and participants were seated around an oval or circular table. This enabled the group to have a clear view of each

other throughout the dialogue. The researcher outlined the proceedings and established group rules, including confidentiality issues and emphasised the importance of honesty in their responses. Group members were assured of universal anonymity and that they or any third party would not be jeopardised as a consequence of their participation in the study.

Consent forms (see appendix 2) were explained and discussed, filled out and collected. The groups were informed that they were free to leave at any time should they feel uncomfortable and that there were counselling facilities available should they be required. Individual information could be withdrawn without explanation. Participants were reminded that sessions were going to be audio-taped and that notes would be recorded simultaneously.

An interview guide with questions and focus group guidelines was developed and utilised to enable a flexible guide as opposed to a rigid one (see Appendix 3). The open-ended questions that were used, explored HCW's perceptions and beliefs about TB and how it affects both clients and HCW. The questions explored the following issues:

- The first impressions felt on initial contact with a TB client or family
- The main issues that arose from the first encounter
- Other problems that arose during the period of care for the TB case
- How clients and families managed issues
- The impact of TB on the client, family and HCW

Each focus group was asked the same questions by the same facilitator in order to minimise possible bias and thus reducing the validity of the findings (see Appendix 3).

As data was generated within the group discussions, participants were able to identify and highlight specific issues that arose when caring for TB clients. These factors were noted and utilised in the development and refinement of

the questionnaire once the thematic analysis had revealed themes and sub themes.

### ***Community Focus Groups***

There were four focus groups held in the community. The first focus group was held amongst health care assistants working with TB clients and clerical support staff. The age range of the group was between 35 to 60 years with an average age of 45 years old. The focus group consisted of eight participants, all female, three Samoan, one Maori, one Fijian/Maori and three European. The participants were eager to be part of the research but doubted that they had anything valuable to contribute. It took time for the group to relax but eventually things settled and the session flowed well. The proceedings lasted 55 minutes.

There were two focus groups of PHNs arranged to enable nurses to coordinate workload and avoid disruption to clients. The PHN group is accustomed to having regular meetings and discussing issues relating to TB. This ensured a synergy between all the participants in the focus groups and the process was very natural and comfortable. One PHN focus group consisted of five participants, all female, four European and one Malaysian; the other PHN focus group had seven participants, all female, six European and one Maori. The first PHN focus group age range was between 45 years to 70 years with an average age of 60 years old. The second group ages ranged between 30 years to 45 years with an average age of 38 years. The groups were convened on different dates and times.

The first PHN group was held in a conference room over a crèche, because access to a more suitable venue had not been possible. The room proved to be noisy, requiring the windows to be kept shut, resulting in a hot stuffy environment. Despite these issues the proceedings flowed well and the group reportedly enjoyed the discussion.

The other PHN group was held in a more suitable conference room. This group blended well from the start and rapport was rapidly established. The two PHN focus group sessions both lasted for approximately an hour.

The fourth group was amongst doctors, from ARPHS, who had varying levels of involvement with the management of TB clients and contacts. There were eight participants, four males and four females, seven European and one Chinese doctor. The age range was between late 20's to 65 years with an average range of 50 years. The focus group progressed reasonably quickly however the members did not appear especially comfortable with this type of research. The session lasted for forty-five minutes.

### ***Hospital Focus Groups/ Demographic Data***

There were only two focus groups in the hospital; these were amongst nursing staff including Registered Nurses, Student Nurses and Enrolled Nurses. Arranging focus groups in the hospital setting proved to be much more arduous than in the community. The Researcher was well known to the community team and they were very supportive of the project. Many appointments were required to explain the project to the Managers of both wards at the hospital. Despite having previously been sent information about the research to the staff, careful communication was required to 'sell' the project and have it accepted. Time was very limited and the project was allocated a strict 30 minutes maximum, to accommodate busy ward schedules. Time was constrained and staff were extremely busy with the wards short staffed. Although immense effort was made to recruit doctors, a focus group between doctors was unable to be arranged.

The first group held consisted of eight participants, all female, four Europeans, two Indian, one Samoan and one Chinese member. The age range of the group was between mid 20's to late 50's with an average age of 48 years of age. The clinical nurse specialist has a pivotal role in this ward and had briefed the staff about the research prior to the session. Although the proceedings took place in the Ward conference room, conditions proved to be very difficult, with many staff coming and going throughout the session to

answer client call bells. The data from this group gave a different perspective, because TB clients were at an acute stage of treatment.

The second focus group had ten participants, one male and nine female. There were three European, two Malaysian, two Indian, one Fijian and two Chinese members. The age group of the participants was from early 20's to late 40's with an average age of 35 years. The session was conducted in the ward conference room as directed by the Charge Nurse. Unfortunately the staff had been directed to attend and had been told they were attending a lecture. Following the lecture there was to be a planned farewell for one of the staff nurses leaving to embark on her overseas experience. Careful explanation and time was spent explaining the information sheet and the research process. During the research a further six people arrived but chose not to contribute to the research. The ideal number of people in a focus group is between six and ten (Vaughan, Shay-Schumm & Sinagub, 1996). There were too many people to allow free flowing conversation. The session was stilted with long pauses and gaps between questions and answers. The researcher needed to use prompts and follow up questions with probing remarks to encourage answers to questions. The duration of the session was thirty minutes and went past very quickly.

All interviews were taped on an audiotape cassette and manually recorded simultaneously. The tapes were transcribed verbatim and then compared and contrasted with the manually acquired transcripts. This data was sent to each focus group member for verification and approval. Following positive feedback the tapes were destroyed as discussed and agreed with each participant.

### ***Focus Group Data Analysis***

The data from the six focus groups were analysed using the general inductive approach, which is related to the grounded theory approach (Thomas, 2006). The analysis is determined by the objectives of the research (deductive) and by repeated reading, reflection and interpretation of the raw data by the researcher (inductive).

Following transcription the transcribed data was presented back to each participant for critique and verification. Following positive feedback from group members, the data from the tapes was thematically analysed through a process of repeated reading and reflection. A coding frame was developed where systematic identification and categorisation of key themes occurred. Following this process, coded text, were inserted into the frame. As new codes emerged the frame was adjusted and the transcripts were reread against the new frame. This process was utilised to create categories that were then conceptualised in broad terms. Originally fifteen themes were identified. The transcripts were examined repeatedly and all possible meanings were considered. Fitting linking data together into six defined categories enabled refinement of the themes. A description of the meaning of each theme was developed and applied. An initial mind map was developed to organise data into a clear manner. This enabled focus on emerging data, which highlighted issues identified and encountered by clients and acknowledged by healthcare workers.

### ***Face to Face interviews***

There were ten 'face to face' interviews conducted (N=10), six in the community and four in the hospital setting. A table showing the demographics of the participants can be viewed as the sample characteristics for face to face interviews (see Appendix 4). In order to minimise that risk that important topics may have been omitted the 'face to face' questionnaire was piloted with two volunteers, resulting in refinement and adjustment to the question structure and order, prior to embarking on the research. The initial guide proved to have too much structure and when applied interfered with the flow of the interviews by obstructing natural flow of conversation. This instrument was further developed and refined so that the researcher was able to probe attitudes and beliefs of HCW in more depth. In addition to that the final question asked for any further thoughts or ideas that had not been covered in the interview allowing the participants an avenue to provide extra information. The purpose of these individual interviews was to explore in depth, HCW's beliefs and attitudes, about TB clients they delivered care to. The 'face to face' interview questionnaire was designed to elaborate on the themes found in the

focus groups. The questionnaire consisted of open-ended questions that allowed participants to respond in their own words. The questions encouraged participant's active conversation and discussion about their feelings and beliefs. The majority of respondents were verbally expressive and cooperative resulting in rich data. The guide ensured all themes were addressed and covered. The questions were all related to TB and included the following topics (see Appendix 5):

- The impact of the TB diagnosis and treatment
- Physical and social isolation
- Stigma
- Cultural and spiritual influences of
- Barriers to treatment and cure
- Views of HCW family, friends and the wider community about TB
- Personal protection measures
- Immigration issues

It was initially intended that participants for the 'face to face' interviews would be selected from volunteers who had already participated in the focus group process. Due to the inability to arrange a hospital focus group amongst the medical staff (thus restricting the scope of the study) it was decided to apply the same sampling frame of the focus groups. The sampling frame therefore was amongst HCW from any professional groups that worked with TB clients either at ARPHS or Ward 68 and 72 at ACH.

Purposive sampling was utilised to select the voluntary participants. Each eligible HCW working in the above sampling frame were sent invitations and information sheets from the appropriate hospital or community Clinical Nurse Specialist. Volunteers indicated their willingness to participate and were then approached by the researcher. A mutually suitable date, time and venue were then arranged between participant and researcher.

The interview guide (Appendix 5) consisted of semi-structured questions that provided a basic structure for 'face to face' interviews while allowing flexibility and freedom of thought of individuals. The first five questions related directly to the impact experienced by the TB case and their family. The next four questions related to stigma and barriers surrounding TB. The final questions addressed the personal affects TB had on HCW, immigration issues and personal protection.

### ***Procedures***

Participants were assured of the confidentiality of their personal responses and the safety of collected information. Each participant was given a Participant Information Sheet and Consent forms (see Appendix 1 & 2). These were discussed; questions were answered and written informed consent obtained.

The 'face to face' interviews were all recorded on audiocassette, following request and approval, from each participant. One interview went beyond the length of the tape and unfortunately the last two questions and dialogue were omitted. The interviewee was able to remember answers and was able to return the data to the researcher. All the transcribed data were returned to each individual participant for critique and approval. One participant was unhappy with her brief responses and added dialogue to her returned transcript.

The tapes were offered back to the participants but there were no requests made for these. Throughout the research process the tapes and consents were kept in a locked filing cabinet. Once the tapes were verified from participants the data was wiped. The consent forms will be retained for a period of ten years. A final written report with the research findings will be delivered to participants who have indicated the wish to have one.

### ***Data Analysis***

The researcher carried out the analysis with a word processor using the general inductive approach (Thomas, 2006). Following transcription of the

data, the transcripts were read several times to identify key themes and categories. The data was then thematically analysed through a process of repeated reading and reflection. A coding frame was developed where key themes were systematically identified and categorised then coded text was inserted into each frame. As new codes emerged the frame was adjusted and reread against the new frame. This process was utilised to create categories that were then conceptualised into broad terms.

Originally 15 themes were identified. The transcripts were examined repeatedly and alternative meanings considered. The application of text into six defined categories enabled refinement of the themes. A description and meaning of each theme was created and applied. The themes identified from the focus group data fitted well with the 'face to face' individual interview data. A model was drawn from the findings to organise and summarise the emerging themes and applies equally to the overall data analysis (see Figure 5.1).

Triangulation was used to ensure credibility of the research findings. It uses multiple methods to reach conclusions (Denzin & Lincoln, 1994). In this study two types of triangulation were used.

- Data Source triangulation was used by interviewing key informants using the same questions.
- Method triangulation by using different methods - i.e. six focus groups and ten 'face to face' interviews.

### ***Conclusion***

In this chapter, the qualitative research methods utilised, were described and presented. The activities described included an overview of focus group and 'face to face' methodology, ethical approval, sampling frame and methods, data gathering methods, demographic information and data analysis.

The following chapter will describe the findings of the research in relation to the attitudes and beliefs of HCW towards clients with TB and how this affects

client care. Issues around stigma will be explored as to its contribution to workers perceptions.

## Chapter Five: Findings

In this chapter the findings of the research are presented. The findings describe how healthcare workers (HCW) perceive tuberculosis affects their clients and their role in the TBD process. The six categories identified from the focus group data assisted with the development of the questionnaire for the individual 'face to face' interviews. The individual interviews revealed more in depth data, validated the previous findings and fitted well into the existing themes. Quotations from the raw data are used to illustrate the themes in the presentation of the findings.

The findings of the focus group data analysis revealed six themes and are

- Psychological/emotional impact of tuberculosis
- Physical/practical impact of disease
- Social/economic impact of disease
- Cultural/spiritual influence on diagnosis and treatment
- Knowledge/information influence on acceptance and treatment
- The healthcare worker's role and influence on care

The first five themes link to each other and are arranged in hierarchal order, which mirror the order in which TB clients experience the impact of disease. The sixth category relates to the HCW role with TB clients. All of these categories are interdependent and interchangeable with strands of categories applying to many or all of each theme. All of the themes are integral in the completion and resolution of the TBD and treatment process (See Figure 5.1).

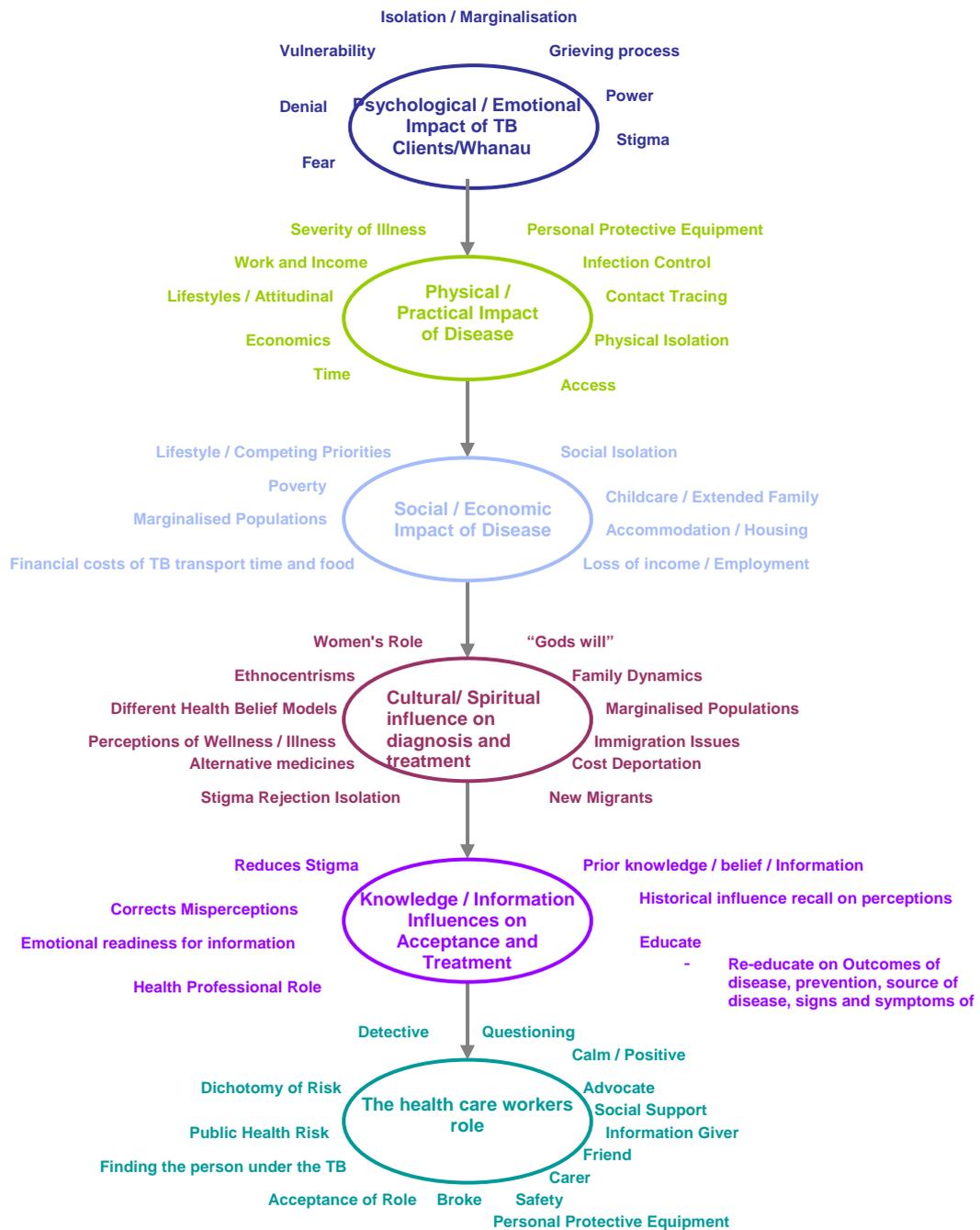


Figure 5.1. Themes from data

The HBM (Chapter Two) assisted with the data analysis and provided a framework in which HCWs' perceptions, beliefs and attitudes were explored. The themes that developed relate to how HCW believe people think and feel about TB, which leads on to the consequences of action taken and the impact this has on the disease process outcome.

HCW described the experience of TB clients as 'putting their whole life on hold'. Clients who were diagnosed with smear positive pulmonary respiratory TB, endured long periods of containment isolation in negative pressure rooms, with each day resembling the last. They reported that clients felt dislocated and isolated from their family, friends and community. All TB clients experience the long duration of medication regimens, required attendance at bi-monthly clinics, monthly blood tests and regular contact with HCW, which is an intrusion and interruption to normal daily activities for people. The majority of TB clients are cured, however the process takes a long time, minimum of six months, making a huge impact on people's lives.

HCW did not view themselves as paramount or central, to TB client care, rather part of a whole process. Most comments related to how HCW perceived TB affected the clients as opposed to what participants felt about clients with TB.

### ***Psychological / Emotional impact of Tuberculosis***

This theme is about acceptance of the TB diagnosis and the response this generates from everyone involved with the disease process. It involves the client, family, friends, extended community and the healthcare team.

This includes the need for the client to accept their diagnosis of TB, accept treatment, including taking the prescribed drug regimen. It also involves the client's close contacts needing to accept the diagnosis and the necessity to be contact traced in order to protect their health. Family and friends need to accept all these issues in order to support the client throughout the treatment. HCW need to fully accept their clients and deliver holistic care throughout the course of the treatment plan. This category is a major theme and relates to the earliest response of client, family/whanau and HCW, from the initial diagnosis of TB, throughout the duration of treatment, to discharge.

The need to accept relates to perceived susceptibility to TB disease, from the HBM. If the client perceives that they are susceptible to TB disease or infection they are more likely to accept the diagnosis and treatment. The level

of perceived belief will directly relate to their response to diagnosis and treatment e.g. whether the client will take medicine for six months.

HCW described clients experiencing a myriad of intense emotions ranging from fear, grief, denial and vulnerability, which contributed to them feeling, stigmatised marginalised and isolated. They believed that clients required empathetic caring and needed time to talk freely, to feel supported and to be accepted.

One nurse mentioned that having TB was a life-changing event for many clients.

*Clients often have to put their lives on hold basically...they can come in here in the morning and are stuck here indefinitely, for however long it takes. It changes their whole lifestyle,... And it turns not only their life....but the lives of their whole family upside down. I would imagine...psychologically... it really does their head in (Nurse B).*

HCW who are involved in the initial diagnosis said that most clients experience a shock when receiving their initial diagnosis of TB. They are emotionally faced with turmoil as they seek to make sense of their sickness. A number of clients are able to process and rationalise the nature of their illness while others struggle to come to terms with the diagnosis.

*Diagnosis is usually shocking, it usually, shocks them completely. There is a big emotional impact, so I think that altogether it comes close to having cancer (Dr. K).*

*It certainly defies the belief of many people who feel perfectly well, when you tell them that they have TB (Dr. H).*

*It is like a two edged sword, some people yes they are very worried what it is, while others are relieved that they know their diagnosis so they can deal with it (Dr. R).*

HCW described how many clients displayed disbelief and denial of the diagnosis. They acknowledged the influence stigma has on client emotions and how some individuals have found themselves completely rejected by family and friends. There was agreement that clients suffer more than the physical symptoms of TB and experience emotional distress imposed by friends, families and communities (World Health Organisation Report, 1998). This was reflected throughout the study by the HCW.

*I met with a family where the father did not want his daughter to stay in his house. He kept asking me to take her away but she was discharged from hospital. He was ashamed of his daughter because she got the sickness (TB). She had already started the treatment (so she was not infectious) and already felt bad about the TB. And he said he did not like her (PHA A).*

Stigma is about having to live with the discriminatory label associated with having TB. Stigma has been experienced historically and remains a problem for TB clients and their families today. People manage stigma in different ways, some experience minimal problems while for others the issues are overwhelming. Living with a discriminatory label fits well with the impact of the perceived threat of TB within the HBM.

HCW recounted that some clients become completely isolated and disconnected from family and support networks. The need to isolate clients with infectious TB often adds to this stigma fuelling the notion that this is a very 'unclean' disease. TB has been considered a 'dirty disease', a 'death sentence' or affecting unclean people for centuries (Johansson et al, 1999).

*For a number of patients it must confirm their fears that "this is the worst thing that could possibly happen to me. Every time someone comes near me they make me put a mask on. Every time the doctors come near me they wear masks and make me wear a mask. It must be terrible if we both have to wear masks. Even when people with cancer have visitors they don't need to wear masks" (Dr. Q).*

This quote also reflects how the use of masks increases the perception of the terribleness of TB for the HCW as well.

*I think it is still that old fashioned belief system of “Gosh we used to put people away for that too, it must relate to somehow doing something wrong or being dirty or not taking care of yourself” (Nurse S).*

HCW discussed how after the client is sufficiently well enough to return to normality, the stigma issue continues to follow them and impact on their lives. It was thought that individuals may be faced with a dilemma, of whether to reveal their close associates details, so they can be investigated, or to alternatively conceal this information. This can create difficulties for public health and pose a risk to the public.

*There is the issue of returning to work... and the stigma from workmates, colleagues and friends and so they don't always write down the names of their close contacts. I have known people not go back to work, or their language school or whatever because they did not want to face the issue at all (Nurse L).*

It was discussed how different clients coped with and accepted TB. A few clients were described as enduring the whole year of treatment without ever accepting the diagnosis. They were compliant with taking their medication and attending clinic appointments because they perceived this as compulsory.

*I remember clearly at the end of Mrs.C's treatment visiting with the Cantonese interpreter. Mrs C spoke only a few words of English and so we had spent many visits communicating with sign language and smiles. Mrs C (through the interpreter) thanked me profusely for coming to see her during the year. She then lamented about the terrible waste of time it had been for me because she had never really had TB at all (Nurse K).*

Many people from countries where there is a high incidence of TB have always believed that TB is a particularly undesirable illness. Stigma can be a

result of existing beliefs about the cause of TB or the severity of the illness (Watkins et al, 2004). Generations of people have shunned and separated TB cases from society and their perceptions have remained consistent over centuries.

*If people have come from a country where they have grown up in an area where TB is always thought about as being something they should never get, it is difficult to change. They will know from their own experience of 30-40-50 years in their country that it is a disaster to have this diagnosis (Dr. P).*

HCW were aware of the potential stigma of TB because they had varied experiences of stigma related to their occupation. Some respondents revealed experiencing initial disapproval from their family circle and having been informed that TB work was not worthwhile.

*I suppose that they think my work in infectious diseases is a bit strange really, they don't think, it's a particularly worthy cause. "Why don't you go back and work with cancer again?" They think it is a much more deserving area (Nurse D).*

*Just talking about relatives and friends ...they always assume that the TB patients are either poor or Asian or refugees...that is their perceptions not ours (Nurse X).*

A further personal experience of stigma was described by a HCW who was given a hard time by her colleagues not involved with the care of TB clients.

*I remember seeing a client once when my non-health protection colleagues came in the car with me to a meeting. All I said was "Gosh some people may think you are my TB patients" Well! I was not popular...the colleagues thought the car was contaminated. Later some of these staff talked about 'all those people with TB' coming to our office and posing a danger! They really thought I was contaminated as well because of the work I do! (Nurse O).*

Other HCW's families and friends were very antagonistic about their work with TB clients and expressed concern about feeling vulnerable about their own personal risk.

*Yes I was scared as well. Yes really fear first of all when I came to work. My folks and family are really quite worried for me going to work with people with TB they said "What does this mean for you..and will you catch it and how will the children and me be safe?" Even though they are not there and they are not looking after the patients (HCA P).*

*If anyone gets sick at home at the moment it's all my fault, "you brought it here". First off I am given the blame. I think they want someone to blame for every disease they get and give me a hard time (HCA B).*

Another group had not experienced any reaction about their work with TB clients, as it was not a topic that was discussed.

*I don't think stigma personally affects me, they know I work with infectious diseases. I haven't been aware that people have changed and don't want to bring their children around. I have not been aware that people have any concerns at all (Dr. S).*

An important revelation and reoccurring theme amongst all the HCW was that people in the wider community of NZ viewed TB as a disease belonging to 'other' ethnic groups. It was notable that migrants from high TB incidence countries shared this view and saw TB as a disease belonging to someone else. This factor is well documented in the literature. TB is frequently blamed on 'outsiders' and most cultures hold preconceptions of TB as a disease of 'other' (Herzlich & Pierret, 1987, Goffman, 1970).

*People in my community often tell me "Oh it comes in from overseas". I always remind them all that we have TB in NZ as well (Nurse S).*

*When I talked to my family about my role, my grandma was astounded and said “I can’t believe that you do all that, it’s an immigrant’s disease and there are New Zealanders more deserving of health care than an immigrant” (Nurse D).*

*A client told me, “There is no TB in my home country; I only developed TB since coming to NZ” (Nurse G).*

*A lot of my friends and relatives think like that...even colleagues...if they are not working in the TB area...that if you have got TB...then you are really poor...and probably living in a house with 20 people...and you have probably come from overseas and you have not looked after yourself really (Nurse Z).*

The psychological/emotional category links with all other categories. This underlying awareness of the psychological effects of TB underlies HCW ideas on the practical impact of TB. In their varied stories HCW recalled some clients who coped very well with TB.

*I remember a client who was admitted to hospital with a broken leg, he had a past history of completely treated infectious TB, some years previously. He was inadvertently placed in a single room and barrier nursing was instigated. The client reported feeling quite pleased because he had his own room and a TV (Nurse K).*

This incident exquisitely demonstrates how the stigma of TB follows some clients around and how health care personnel, without the correct knowledge, add to this process.

*Emotions are essential to effective coping. One’s responses to feelings may create the need for coping with the emotions so that one can effectively cope with the situation (Benner & Wrubel, 1989: p. 97).*

### ***Physical/Practical impact of disease***

This theme is about the need to feel well in order to return to a state of good health and feeling normal. This theme reflects the physical effects encountered by a client ranging from being very sick to feeling quite well. It also addresses the practical issues experienced by the family with a sick family member. The practical impact begins in hospital with isolation and this is perceived by some HCW as difficult for the client yet necessary. Emotional issues often compound the physical and practical effects.

The need to feel well relates to the perceived severity of the disease in the health belief model. This corresponds with the clients and HCW's responses towards positive actions in the belief that wellness can be achieved or maintained e.g. Infection control precautions and isolation.

The isolation process is necessary while the client remains infectious to maintain safety and prevent possible further spread of disease. Infection control and protective masks are important but the initial psychological impact of their use is significant. Isolation creates problems for the client with difficulties around communication and financial problems and is recognised as an issue by staff. Visiting times are restricted and children are not permitted to visit TB cases. Many may choose not to visit at all.

*Some won't come and visit at all. Everything is done by phone. There are some who come and visit and are all smiles, when the person gets home they find they've got two suitcases outside the front door and I have seen that happen three times (Nurse H).*

*I suppose that isolation is a necessary evil in order to prevent further harm. Because really it's not for the benefit of the case (Dr. P).*

Talking without being able to visualise each other's faces can hinder effective communication. Clients have the additional concern about the care of the family at home and how they are going to function financially.

*The discomfort they have.... They always have to wear the mask.. they have no TV. They are isolated from the rest of the world. They have children at home. They've got work, businesses and I don't know how they manage (Nurse K).*

HCW recognised that the client and family need to feel safe and protected within the hospital environment. They felt that the perceived lack of nurturing that may occur when isolated and the practical obstructions that exist create a barrier to feeling safe. Some of the main issues HCW mentioned were related to the physical effects were being lonely, hungry, tired, having been exposed to an infectious disease and memory loss. All of these factors contribute to patient's cumulative increased stress levels. It was identified numerous times that clients felt hungry, because the food offered was culturally different for them, which reduced their ability to function effectively. Often the worry about the practical home arrangements eg: childcare impacted on the recovery phase and added to clients becoming anorexic.

*Sometimes families get themselves into very difficult situations. Take a young mum with a 3 year old that suddenly finds she is admitted... and this can, from a respiratory point of view, require hospitalisation for up to 6 weeks. So suddenly a friend has to pick up caring for the child. that would not normally expect to.. and this is a huge ask for anybody. And then the poor mum who sits in hospital, who can't see her child...who sits and pines... Won't eat... and tries to keep her spirits up... I find this really hard (Nurse H).*

HCW identified a need for the client and family to be safe and the importance of adequate measures in place to keep them protected from disease. Initially for the client, being safe is about forming trust relationships with their HCW. HCW expressed concern about safety of their clients. They need to be able to trust that their rights will be respected and confidentiality maintained. This poses a dilemma where client's rights are weighed against potential public health risk and the protection of exposed and potentially infected people.

Being safe and protected relates to the perceived severity of the disease category of the health belief model. It relates to observing risk reducing behaviours by wearing masks appropriately coupled with proactive positive behaviours of cooperation with contact tracing.

HCW felt the impact on themselves when having to wear personal protective equipment and the need to maintain physical isolation between them and the client. They lamented about how this was a shame and empathised with the clients about their incarceration and loneliness but at the same time recognised the public health risks.

*I first of all think...what a shame. How are you feeling? There is that kind of human...how well is this person? And then I start thinking where did they come from? Where did they get it from? And then I start thinking so what are the risks? What are their other risks? And what are the risks of them having infected others...how do we manage that? (Doctor C)*

Contact tracing was viewed by HCW as another important area of conflict with client rights and public health. It is essential that exposed contacts rights are respected as well and that they are given full information and offered screening and treatment as needed. Often contact tracing can take place without revealing details of the source case. This makes contact tracing more difficult and gaining permission to reveal the index cases personal details ensures the process runs more smoothly. HCW recounted a range of client reactions and how many clients are faced with the dilemma of whether to reveal contacts or not. They may feel fearful that they have infected other people and worry about subsequent negative reactions but at the same time want people protected. All individuals are different and will react in variable ways and the level of support they experience may influence their decision of whether to disclose or not.

*There is fear as to how many of the family have I infected and whether they are going to become sick. It could drag, it could bring them together as a family or it could actually blow them apart. It depends how strong the*

*ties are originally and how functional or dysfunctional the family structure is (Dr. P).*

*For the families it (contact tracing) is another thing they have to go through. It can sometimes be stressful and they can be worried and concerned over the days, weeks and months while they are having investigations “What if I am found to have TB as well and how is this going to effect me?” (Dr. Z).*

All respondents unanimously viewed infection control as an integral part of their work place. They believed that they had extensive training in control measures and felt comfortable about adhering to precautions that were in place. Personal protection equipment (PPE) use was not viewed as an obstruction to the client/healthcare worker relationship or in preventing positive rapport between them.

*In 99.9% cases I have got to completely and utterly wear masks, gloves and gown the whole of the time..... (Nurse H).*

*Infection control precautions are very, very important. If there is anyone I think could be at risk I make sure they are wearing a mask (Nurse J).*

The accurate knowledge HCW had received meant that they were not concerned about possible transmission of TB through them to their own family or friends. They viewed personal risk as minimal and all felt extremely comfortable about working alongside TB clients and their contacts.

*I think infection control precautions are important. Let's not get obsessive about it but it just becomes part of the job (Dr. B).*

Most HCW felt quite secure and protected and were confident with PPE use. This may not have always been the case where some described having felt uneasy and at personal risk during the initial period of working with TB clients.

*I felt a little anxious about the whole experience...the mask and the closed room. I think if you are working in those situations frequently it becomes second nature and you stop thinking about it. But the first few times it felt quite intimidating, the negative pressure room, sealed doors and the mask wearing (Dr. P).*

Problems with medication were discussed at considerable length and identified as an inhibiting factor contributing to compliance. These included clients having to take too many tablets, the long duration of drug regimens and the occurrence of unpleasant side effects. These were all thought to create a huge barrier to successful completion of the course and cure of the disease.

*The medicine is too much; this for the old people is a problem...(HCA R).*

*Just the amount of medication and the long period, which it needs to be taken (Dr. Z).*

*In terms of treatment the number of tablets people have to take and the potential side effects are a barrier. That is worse for some people than others, some people seem to tie up and take their medication and never bat an eyelid while others find the side effects huge (Dr. R).*

### **Social/economic impact of disease**

This theme is concerned with sustaining relationships, ensuring that social reactions that happen or need to occur take place, keeping the family connected during the experience of TB. Social support was seen by HCW as being important yet many observed difficulties in the social support received by some clients. The economic response relates to the financial burden that occurs initially and in many instances remains ongoing.

The need to sustain relationships relates to the perceived threat of the disease, as outlined in the HBM (Chapter Two). This includes families coping with the burden of social isolation and the economic costs associated with the

disease experience e.g. HCW reported that many families experiencing TB felt isolated, alone and vulnerable due to the nature of the disease.

Social support systems were seen by HCW to vary amongst different family units and work places. Many families had strong family networks while others were isolated and alone.

*If a patient is really sick for instance, in end stage renal failure, the problems are enormous. The social issues are endless. I am thinking of a family that lived in my area they had big, big social issues, about an elderly person living at home with them with other problems to do with being old as well. The dynamics that arose in the family were major, with other family members being sick, the fear of catching TB and feeling vulnerable (Nurse C).*

Sometimes TB clients were observed to find their support from work colleagues who rally together to help clients achieve wellness and become cured. In a factory setting where clients may have had close contact with colleagues many may be diagnosed with latent LTBI. In this instance it may be necessary for the nurse or health assistant to deliver medication twice weekly by directly observed therapy (DOT) within the work environment.

*I went to a group in a factory and because the issue of TB is all out in the open there, the people that are on medication have formed a support group. They keep each other 'crisp' and know exactly how many tablets each person takes and what stage they are at in their drug regimen. It was actually great...everyone in the factory knew..... and there was no blame, no shame and it was really good. One man said don't drop my medicine at home just drop them all into the factory (Nurse W).*

The economic cost often does not end around hospitalisation, where non-working clients are unpaid; costs also mount up for the family from petrol, car parking and childcare. HCW said that the ongoing need to attend clinic is also an issue for some people. Some people feel not valued in terms of their time

when visiting clinics at a given appointment time and then having to wait for hours.

*Another issue is having to pay for parking at the hospital. One of my clients expressed the stress and said they were sick of going to the hospital, to attend appointments, because when they came out they had to pay large amounts... and having to wait so long to be seen ...the waiting time adds up and that means they have to pay for it at the end... extra hours unpaid from work and car parking payment at the end.. so they get anxious and grumpy ( Nurse B).*

Competing priorities were seen as barriers to follow up care and clients being available to keep appointments with HCW. Some people were perceived as over committed with work priorities while for others TB was not going to have a major impact on their life.

*So I think it is quite a hassle factor. " I have to see you every month and I have to see the doctor, oh it's a real hassle" They haven't got time for it anyway and its hard for them to understand that although they feel and look well they still need to spend the time completing the follow up (Nurse S).*

*This particular person because of her work commitments, the workplace is understaffed and she feels a lot of pressure from her managers to be there, doesn't see her health as a priority (Nurse A).*

A further important issue identified by the HCW was that of diagnostic delay from multiple causes. HCW saw this as a problem because prolonged delay can contribute to the client becoming severely unwell and a greater chance for the spread of infection. There were instances reported where people had visited their GP on numerous occasions and were finally diagnosed after many months of symptoms. These visits usually involved multiple investigations, several courses of antibiotics, time and expense for the person involved.

*Another barrier is the doctor not picking it (TB) up fast enough, people presenting to the doctor numerous times with a cough that is not resolved and finally having a chest X-ray (Nurse P).*

*If the diagnosis is delayed and they are infectious, they have a greater chance of infecting others...that is a barrier (Dr. R).*

Another diagnostic delay was attributed to the cost of visiting a family doctor and the individual's inability to meet the cost of the medical bills.

*Others I think is cost, not being able to afford to go to the doctor (Nurse J).*

### ***Cultural/Spiritual influences on diagnosis and treatment***

This theme relates to the important role of an individual's social identity. Cultural and spiritual influences can be an intricate part of who an individual is, where they come from, where their roots are and can be the essence of who someone is. HCW observed who the TB client is greatly impacts on the way some people manage their disease and reach recovery. Immigration issues impact on individuals' identity and can directly affect their cultural and spiritual well-being. These influences are important to some clients while others appear to manage the disease without this input.

The cultural and spiritual influence on diagnosis relates to perceived susceptibility to TB and is identified within the HBM as a modifying factor. The client is influenced by this susceptibility to the disease and personal vulnerability of themselves, their family and the community. This would influence the likelihood of taking action or not.

HCW talked about how some clients were assisted by their strong belief in God while sometimes historical beliefs about TB affected clients and their families in an exceedingly negative way.

*I think what a patient said to me last week...listening to him telling his story and seeing what sort of person he is...He refers to a spiritual side of his life and then with all this disease and the TB. He said he had done things before and that is why he is sick (HCA R).*

It was acknowledged by HCW that different ethnic groups coped with TB in different ways and it was sometimes thought to be preferable to be diagnosed and treated in NZ as opposed to their home countries. A HCW recalled a story about a visit she had recently made.

*I visit a patient last week and he cried and said "you don't know how much it means for you to come and listen to me and bring my medicine to cure me. You are a ... ethnicity person and I am a ... ethnicity person, you make my day". He said "I am living in NZ and I am struggling with this disease and you know how much TB is a major, major thing in my home country. If people knew about this at home they will cast me out and ignore me" (HCA P).*

Since the emergence of MDRTB, treatment has become exceedingly expensive and more difficult to treat (Das et al, 2006). As a direct result of this, the government has adapted a much harder line stand on immigration and health requisites (NZ Immigration Service, 2005). There has been a distinct change from TB clients in NZ previously receiving free treatment. Varying attitudes were noted about this stance with some professionals supporting tougher regulations and viewing them as a strategy for reducing the incidence of TB in NZ.

*As far as immigration and TB goes, I think it is (regulations) pretty reasonable. Except some people we need to get out of the country faster...We have had a couple of cases with very serious multi drug resistant TB where the process has meant we have had to look after these people for months. It has been at monumental cost... (Dr. Z).*

Other HCW were less concerned about the economic issues of treatment for non-residents. They were primarily concerned with the provision of treatment

for all and reducing public health risk. In some cases the policy change has resulted in anxious clients and people have gone into hiding.

*Dealing with people for immigration, they are more concerned about cost and they have heard the rumours that TB isn't free any more and that they could be sent back (Nurse H).*

*If clients require hospitalisation or treatment and they are on visas, they will not be granted residency in NZ. I think that it will have a huge impact and we are going to see more people disappearing within NZ with their TB. The gentleman who died recently was probably an over stayer hiding. We are going to see more of this and have more people we are unable to see or treat (Nurse M).*

Changes to Immigration Policy have, at times, impacted on the management and follow up of TB cases and their contacts. HCW recounted how tougher migrant policies have meant that some clients have disappeared and gone underground. In some instances clients have had their residency denied, some people have been deported, while others who have left the country are unable to return to NZ.

*I had a young guy last year with pleural TB on full medications that was not getting better. He was multi drug resistant and had to go to the hospital twice a day. His family decided to send him back to China because this was interfering with their schedule of day-to-day living. Now the kid can't come back and he is stuck....and the family are angry with that...but that was their choice. Twice a day was too much; he was interfering with their business and their lifestyle (Nurse S).*

These recent changes to Immigration Policy have left some HCW unaware or unsure about the potential effects on TB clients.

*Immigration seems to be a really grey area and no one seems to know what the guidelines are, they seem to change the goal posts and it*

*becomes really confusing for all, health professionals and clients; it seems that there is a need for greater, clearer guidelines (Nurse A).*

Some HCW expressed concern that new migrants to the country experience a huge amount of stress, needing to embrace a totally new culture, different foods, political systems, education etc. The stress of all these changes can impact on their health adding to their anxiety and problems. They may feel different in a strange country and are fearful of anything that can contribute to them becoming rejected.

*There is a group of new patients that I have. They are new migrants to the country. They are going through a lot of stress...and that may be one of the reasons that they have TB now. To get themselves cured from TB is important because they need the clearance for immigration. If they have just got a new job and they don't want the workplace or the boss to know this is a big problem...so it is a big stigma for them (Nurse D).*

Anybody can become infected and develop TB disease however it disproportionately affects the most vulnerable populations (Turnbull, 2003). Many respondents reflected on how often already disempowered people developed TB disease. For some people it may just add an extra burden where as for others it can add huge strain to an already difficult life.

*Everything becomes a huge cost to families and they actually don't have a lot of money...families that are struggling just can't afford this! (Nurse P).*

*Its just another blow, for a client that already feels stink, this (TB) just adds to it (Nurse H).*

*Quite a lot of them are underprivileged and I am sure for many it is just one more burden on top of almost a life full of burden. I think a lot of people have given up on their lives and we get both patients and families who do not have any specific interest in doing the best for themselves (Dr. Z).*

Some cultures have gender issues connected with TB, which affects people's beliefs. In some cultures, it is believed that men may have developed TB because they have been working hard, long hours. In contrast, women are more discriminated against. The women may have contracted TB as a result of promiscuity or wrong doing in the past. Stigma is closely related to contextual factors such as gender roles and can result in concealment (Johannson, Long, Diwan & Winkvist, 2000).

*I remember a young Indian woman who had come to NZ for an arranged marriage. Although she knew that she may have TB she went to great lengths to conceal it because she was staying in her husband's family home. She was afraid that she would be sent back to India and bring great shame on her family (Nurse J).*

### **Knowledge/Information influence on acceptance and treatment**

This theme relates to 'the need to know' where knowledge is required and disseminated to clients, families, TB contacts, the wider community and health professionals. Knowledge is an essential component of understanding and acceptance of TB.

The need to know relates to the HBM as raised awareness through mass media, when information and education delivered by HCW, serves as a cue to take action. The type and level of information may either trigger acceptance and positive response or exacerbate discrimination and fear.

It is vital that the information given is correct, timely, adequate and reinforced as required. A study in the USA amongst graduate nurses working in a HIV/TB unit, suggests that some teaching sessions delivered to HCW, resulted in less positive attitudes because of their increased perception of risk (Messemer et al, 1998). Further literature from a study in Italy suggests that while some aspects of TB education are well covered, some topics are omitted, resulting in clients feeling fearful and uncertain thus discontinuing medication (Moro et al, 2005).

The right information fits well as modifying factors in the HBM, influencing the client's response to diagnosis and complying with treatment regimens. Appropriate education for TB clients is vital to ensure they have the best possible chance of understanding, conceptualising and coming to terms with their diagnosis. Information should be given in an empathetic way where the HCW sits alongside the client and delivers positive messages in a reassuring manner.

*Most people don't have a very good knowledge about TB. You have to present TB as a disease that has been around for thousands of years; it is serious but very curable and easily dealt with (Dr R).*

*You need to give them lots of education to start with and continually repeating key messages makes for a smoother process (Nurse J).*

HCW agreed that families must receive information that enables them to understand the disease process and observe protective measures so that further transmission is averted. They discussed how an explanation must be given about contact tracing, the importance of this and how it will be conducted. They thought it was important to deliver information to clients so that it was clear and understandable. The cause of stigma associated with TB can be a result of misinformation about TB transmission (Auer et al, 2000). HCW found that sometimes clients and families felt very anxious and information sessions reduced this. A major discussion point was the need to repeat the information as clients and families were at times in a state of shock or disbelief.

*I find with clients and their families when they have just been diagnosed that you have to keep readdressing the same question...they will ask you "Why have I got this? What are the symptoms?" and I just keep readdressing it and all the health workers that go in have to keep readdressing it...(HCA L).*

HCW repeatedly felt that overcoming stigma was directly linked to providing information to the community. The need for language specific resources delivered in a culturally appropriate way through a variety of media was widely suggested.

*Education of these communities where TB is common may not have English as a first language. Education needs to be delivered in their own language and presented in a way the concepts can be understood easily (Dr. R).*

*I think we need to have community training, just to explain to them. If you give them knowledge about what TB is and how medication works it will stop them thinking TB won't go away (HCA. N).*

Several respondents suggested that community education should take place at an early stage in the education system. Eliminating stigma was a generational issue that would take time and concentrated effort, delivering programmes through preschools and schools, as well as mounting media campaigns could be effective.

*I am just wondering, whether we could educate in preschool and schools, not only here in NZ but also in the Pacific countries as well. I feel that it is an opportunity to influence the education of children in this small specific area and the message could be incorporated and taught elsewhere (Dr. A).*

*I see these big screens out there that I read things that are nothing to do with me. I think health messages about TB would be really useful (HCA. Y).*

HCW also spoke about a lack of information amongst some staff that did not routinely work with TB clients. They discussed how important and necessary it is to educate hospital staff, community staff, practice nurses and others. HCW said that details about signs and symptoms and the way it is spread are some

of the important points to be emphasised. Uninformed health professionals were observed to act illogically and were fearful about their own risk.

*I remember the first time that I came across a TB patient...My initial thought was ...I hope I don't get this and how safe am I? And even though I had just done the training I was fearful that if I got to close to this person I might get it... because I remember the history behind it. It killed a lot of ...ethnicity in the 1950's and I thought I hope I will be ok (HCA B).*

*The first time I came into contact there was real fear...now that I have been working here .. it is like so the patient has got TB so what? It is not a problem now (Nurse J).*

Even members of the TB control team described initial misgivings about their personal safety and vulnerability. Many studies revealed HCW expressed the need for comprehensive programmes for themselves. Some reported feeling inadequately prepared for their role in TB control and felt they had received inadequate training (Dimitrova et al, 2006, Mishra et al 2006, Moro et al 2005, Messemer et al 1998).

Many HCW involved with TB clients expressed their feeling of being unprepared when first working in the area. This contributed to them being scared of becoming infected and worried about spreading disease to their loved ones.

*It was just in the beginning that I was scared. Sometimes I asked the nurse that I worked with "Maybe I got TB, I feel sick" (HCA. Y).*

*When I first started working with TB clients I was quite ignorant as well. It has taken me quite a while to learn it all up but now I feel ok (Nurse C).*

Extensive orientation programmes to TB work had not, in isolation, alleviated these concerns. It is essential to have accurate timely knowledge, to develop acceptance and to feel comfortable with infection control procedures to

overcome initial fears. Education programmes should be comprehensive, ongoing and provide opportunities for discussion and debate.

Other HCW felt they had an extensive knowledge about TB and found TB work both challenging and rewarding.

*I have a reasonably grounded knowledge of TB and feel comfortable about working alongside TB cases and their families. I enjoy the work and think it is very fulfilling (Dr. L).*

### ***The healthcare workers role and influence on care***

The data largely reflected how the participants felt TB affected their clients as opposed to what they felt about clients with TB. They had very definite ideas about their role and how this contributed to the various aspects of TB client care.

The role of the HCW and influence on care is demonstrated within the HBM as a modifying factor in the clients' response to the threat of disease. The role was viewed as pivotal in modifying the negative effects of stigma associated with TB by providing education and assisting with normalising the process of the TB experience.

Rich descriptions of the HCW's roles were revealed from the focus groups and individual interviews. These are summarised in Figure 5.2. These roles included acting as an advocate or broker, a carer, a friend who provided information social support and education to their clients and contacts.

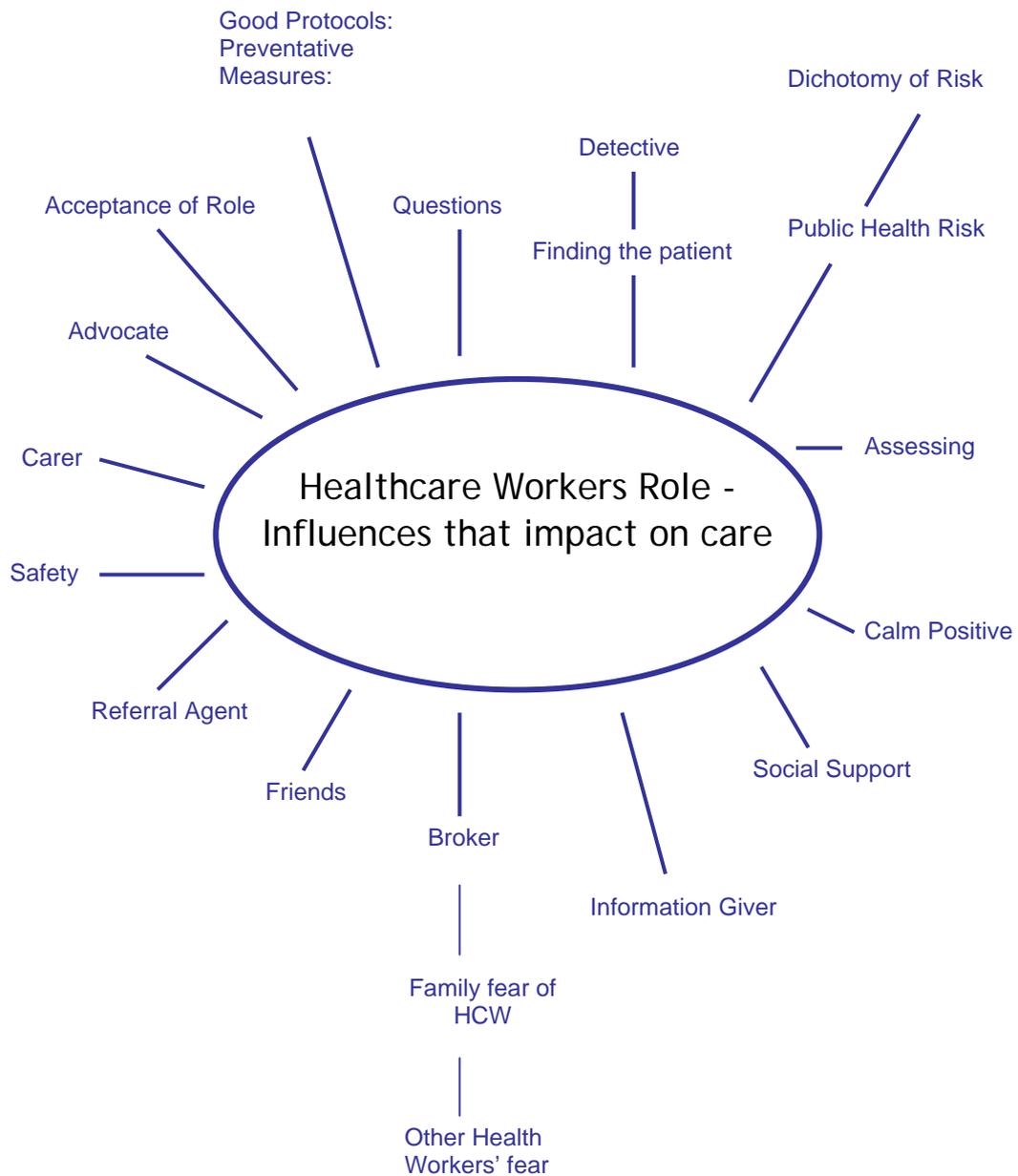


Figure 5.2. Healthcare Workers Roles

There was agreement that the roles needed to be actioned with empathy and care, giving positive affirmations to clients in a calm manner, throughout the TB disease journey. They discussed the frequent need to adopt detective skills in order to find recalcitrant people or missing clients. This role also stretched to finding the real person hiding under the TB mask and truly getting to know them.

*I am quite keen to meet them, I am going to be tracking down all those defenceless kids to save the world... and I go out with the full idea of disclosure (of information) (Nurse S).*

Close relationships take time to develop and often require HCW to invest quality time to 'be with' their clients and listen carefully to anxieties and concerns. Several HCW expressed the power of touch as important and how this had been invaluable in cementing relationships and helping a client to feel safe and normal.

*One client told me "I really appreciated that guy sitting on my bed, the doctor sat down on my bed and touched me and that was huge because I just heard that I'd got TB" (Nurse G).*

*I always touch them to make sure you let them know that they are ok and that you are really looking forward to them coming home (Nurse L).*

*For some of them my visit is a reason to get up in the morning, twice a week to tidy the house. When you are lonely sometimes the nurse visiting with the medication is the only person the client will see. The clients become quite attached to you as the health professional. The clients know the nurse is visiting because they are interested in them and interested in making them well (Nurse E).*

There was a significant difference in the way that care was delivered to clients. While some HCW were concerned with delivering care holistically on an individual basis, others were more concerned with the medical aspects of care of clients, being concerned about compliance and completing treatments.

*I don't delve into the deeper psychological things in terms of whether they have been scarred and so forth. I focus on whether they have taken the medication and if they are tolerating it. I don't spend much time actually asking them deeper psychological things (Dr X).*

The majority of literature found pertaining to HCW's attitudes and beliefs revealed that adverse relationships were a major barrier to compliance and successful completion of TB drug regimens (Dimitrova et al, 2006, Godfrey-Faussett et al, 2002, Hawker et al, 1999, Johansson et al, 1999). The majority of respondents enjoyed their work with TB clients and particularly valued the long, intense relationship they enjoyed with each client.

HCW discussed the long length of treatment and the care relationship that developed as a result of this. Some noted that when clients were discharged for many it is a great sense of relief that treatment had come to an end. Some HCW described client's celebrations on their final discharge from TB services. Many staff talked about celebrating with their clients and having contributed to these celebrations by providing incentive presents they had obtained from Lung Health Auckland. Other HCW described how some clients once their medication is finally finished just want to end it and move on.

*I do have one man and he is over it. He has had so many people telling him that he had TB for ages...and he could not care less... so there is no way that he will go for a follow up appointment. As far as he is concerned the medicine has finished and that is it. He is over it and the problem is gone (Nurse A).*

The HBM was helpful with the analytical process and provided a framework to reflect decision-making in relation to acceptance and compliance with TB diagnosis and treatment (see Figure 5.3). Using three main themes a model was developed:

- Clients perception of risks of TB
- Inhibiting factors in decision making in relation to accepting the diagnosis.
- Facilitating factors in decision making about accepting the diagnosis.

It is essential that the HCW care and support their clients through the TB illness and recovery phase in order to achieve cure. A patient –

provider relationship based on collaboration and trust is likely to encourage the client's acceptance of the diagnosis of TB and accept treatment.

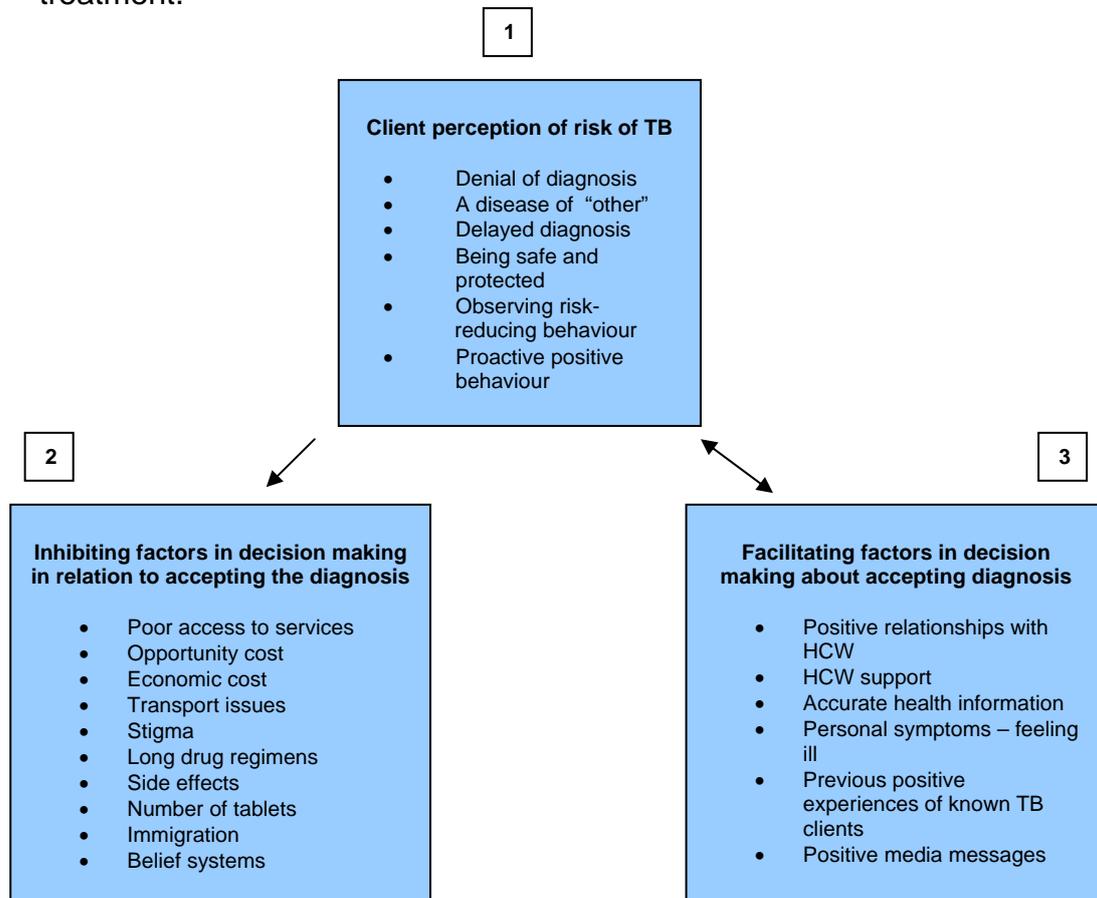


Figure 5.3. Factors associated with the client's response to the TB diagnosis and process using the Health belief model framework.

In this chapter the data from the focus groups and the 'Face to Face' individual interviews have been analysed. A model has been developed from data that revealed factors that influence TB client's willingness to accept their diagnosis and treatment. The analysis reveals that clients with TB experience a complex matrix of experiences affecting them psychologically/emotionally, physically/practically, socially and economically. Cultural and spiritual factors influence the manner in which the TB client copes with the diagnosis. The TB client is placed within the context of their life and the HCW strives to work alongside the TB client to break down the barriers to TB treatment and successful cure.

Chapter Six summarises the research study and makes recommendations. Firstly issues are identified, attitudes and beliefs about TB clients are challenged and the development of an ongoing staff development TB education programme is discussed. Strategies about improving client outcomes will be outlined. The limitations of the study along with proposed future directions will be suggested.

## Chapter Six: Discussion and Recommendations

This purpose of this chapter is to discuss the key findings from the literature review, the focus groups and the 'face to face' individual interviews. Some recommendations are suggested and the limitations of the study are outlined. The implications for future research are discussed. The plan to disseminate the results is described followed by a conclusion.

### ***Key findings***

1. The findings were unexpected. HCW described their perception of how TB clients and families experienced TB, the factors that influenced the experience and their role in working with TB clients.
2. HCW perceive that TB clients and their families endured life-changing experiences. They believed that clients were affected psychologically, emotionally, physically, practically, socially and economically. They identified that the client's own personal identity influenced by their cultural and spiritual beliefs impacted on their TB experience. This varied from being greatly affected to having little affect at all. HCW perceived that the amount of relevant information received and understood influenced they way the TB clients managed their illness. They viewed a positive HCW and client relationship as integral to successful care and treatment completion.
3. The data generated revealed that clients experienced issues that were either inhibiting or facilitating factors depending on their perceived risk of developing TB. These findings were applied to the HBM framework.
4. Every HCW group functioned differently and performed specific roles. All groups were essential for successful TB treatment and functioned as part of an overall interdisciplinary team. Doctors were most concerned with diagnosis, drug regimens, medication completion and clinic attendance. This role fits well with the 'medical' model of care. Nurses adopted a more holistic approach and were concerned with everything that related to their clients and families. Health care assistants were

task orientated and mainly focused on completing the specific task e.g. giving a DOT.

5. Stigma remains a major ongoing issue for TB clients and affects clients, families, communities and HCW. Continuing stigma has resulted in the belief that TB is reported to be a disease belonging to 'other'. The stigma surrounding TB appears to be as strong as it has been for hundreds of years.
6. Significant gaps in TB knowledge exist for clients, families, communities and HCW, which contributes greatly to the stigmatisation of clients with TB.
7. HCW involved with the Auckland TB programme chose to work in this specialised area and displayed positive attitudes in regard to their TB clients and families.
8. Immigration issues contribute to stigma and can create barriers for access to TB investigation, treatment and cure e.g. adverse affects on marriage prospects for some female TB clients.
9. Although TB investigations and treatment are mostly free in NZ, having TB imposes other costs to clients and families. These costs involve monetary cost, opportunity cost and the emotional cost resulting from the physical and psychological effects that clients encounter.
10. With the emergence of multi-drug resistant and extremely drug resistant TB, the care of some TB clients has become more complex. Clients already suffering from immune compromising conditions or living in adverse conditions find the diagnosis of TB an additional burden.

In the literature, the setting of the research occurred in countries with high incidence of TB, poor socio-economic conditions where healthcare resources were scarce. Only one study had a dedicated TB control programme. This is in stark contrast to the NZ setting where the TB incidence is low, the economy is robust and there are dedicated funds for TB control. Auckland has a regional TB control team.

### ***Findings consistent with literature review findings***

1. Much of the research confirmed the finding that TB clients suffered greatly from having TB and experienced similar affects as described by HCW in the research findings previously discussed. This finding demonstrates the need for staff to portray empathetic care and suggests that courses in counselling skills may improve practice within the TB team.
2. Stigma associated with TB creates a major barrier to acceptance of the TB diagnosis, treatment and cure. This was apparent in the literature and a major finding in the study. Community TB awareness programmes could attempt to address stigma by improving TB knowledge which would improve the TB client's experience.
3. Knowledge and information about TB is generally poor, as described both in the literature and in the study. This lack of knowledge relates to clients, families, communities and some HCW. Ongoing in-service TB education programmes would improve practice and result in more positive outcomes for the TB client.
4. Different HCW groups play different roles in TB care; they are all integral to the TB process and compliment each other. Team building programmes, where multi disciplinary TB team members, have regular meetings and jointly present case studies, could foster deeper understanding and appreciation of each other's role. This would improve care to TB clients because HCW would value each other and refer TB clients to each other more appropriately.

### ***New or unexpected findings***

1. HCW in other studies displayed negative attitudes towards TB clients, which resulted in high rates of client non-compliance and lack of cooperation with treatment. There was only one study, amongst HCW working in a TB control team, in Nicaragua, which compared favourably with the participants in this study. The HCW also exhibited compassion and care, for the TB clients and after their initial orientation period, were not concerned about becoming infected (Macq et al, 2003).

2. The inhibiting factors for TB clients to accept their diagnosis and take proactive care were much more accentuated in the studies found in the literature. This could be because of the lack of resources, social conditions and reported negative attitudes of HCW.

### ***Limitations of the research***

The research study was focussed on one disease (TB), in a single geographical area of Auckland, NZ. The Focus Group and individual 'Face to Face' interview data analysed in this study reflect only the knowledge and attitudes of the HCW who participated in this study and not necessarily those of the whole TB control team.

Although the participants were not chosen randomly, the entire population group of HCW received invitations and had the opportunity to participate. The response rate was high and data generated from the focus group interviews and 'face to face' interviews provided sufficient depth and richness to provide the basis for a theoretical model. The possibility of selection bias could be considered because the research participants were drawn from HCW working alongside clients with TB. As they belong to a motivated group their attitudes and beliefs may be more positive and not reveal more negative attitudes or problems.

Focus Group discussions took place in a very open atmosphere. Many of the ideas were repeatedly expressed in different ways. By using the two methods of data collection, focus group interview and individual interviews, triangulation of methods was possible and helps to establish trust in the findings. There was only one interviewer involved with both the focus group and 'face to face' individual interviews which ensured the questions were applied in a consistent manner.

### ***Recommendations***

A report of the research findings will be presented to management of ADHB and the Auckland Tuberculosis Control Programme, which will include

recommendations listed below. A report will also be sent to the Auckland region Y Ethics committee and the ADHB Research department.

The research indicates that there are three types of recommendations relevant to the findings:

- (A) Health promotion and community health strategies
- (B) Recommendations for the Auckland TB control programme
- (C) Future research strategies

### **(A) Health promotion and community health strategies**

A1) To develop and extend TB awareness programmes to community groups, delivering positive messages to heighten awareness, correct misinformation, dispel myths and reduce stigma. Appropriate resources will be used and where possible translated material will be made available.

A2) To ensure that TB education programmes that are delivered to clients, their contacts and community are accurate and illustrated with appropriate resources. The programmes should discuss the duration of treatment regimens and the consequences of non-compliance or non-completion.

A3) To assist communities with community development programmes to identify and address factors that contribute to the spread of TB within households and the extended community e.g. inadequate housing.

### **(B) Recommendations for the Auckland Tuberculosis Control programme**

B1) Ongoing staff TB education programmes should be developed and implemented. These programmes should address gaps in current knowledge in both the hospital and community settings. The sessions need to include: TB epidemiology, pharmacology, and guidelines for the correct use of PPE, especially when used for client isolation

requirements. A series of teaching sessions looking at the current challenges facing TB control would be helpful in demonstrating the need for completion of drug regimens and the careful management of drug side effects.

B2) A TB destigmatisation campaign using multi media should be developed. A programme could address the stigma surrounding TB and ensure people have the correct perceptions about the illness.

B3) Clinical supervision or counselling programmes are offered to all HCW involved with the care of TB clients. HCW are frequently placed in stressful situations and become very involved with family dynamics. Debriefing in these situations is always useful.

B3) Investigate the possibility of reducing containment isolation time so that TB clients can recuperate at home until smear negative. This policy is carried out in other centres.

B4) HCW involved with TB clients should attend counselling skills programmes to enable them to manage the complex issues they encounter when working with their clients. This should include developing awareness about when issues require referral to more skilled and experienced professionals.

B5) Clear guidelines around health and immigration policy should be developed to ensure appropriate care is delivered to all clients with TB.

### **(C) Future research strategies**

(C1) A study amongst HCW not directly involved with the care of TB clients would be useful to determine their attitudes and beliefs about TB clients. These HCW are to be drawn from diverse ethnic backgrounds, cultural and socio-economic groups. This study would be useful in establishing a baseline of HCW attitudes so that an educational awareness programme could be developed and applied to the various groups requiring

education. This study could include HCW from all regions of NZ providing valuable insight into the attitudes and beliefs of generalist HCW from the whole of NZ.

(C2) There is a need to develop specific evaluation research about current community TB awareness programmes. Although anecdotal evidence suggests that programmes have increased cooperation and compliance amongst TB clients and contacts in various ethnic groups formal evaluation has not occurred.

### ***Dissemination of Results***

Preliminary research findings were presented at a National TB conference in Sydney, New South Wales, Australia on March 22<sup>nd</sup> 2007 and received positive response from the audience. The research findings will also be published in an article in The International Journal of Tuberculosis and Lung Disease. It is planned to present the findings to the New Zealand National Tuberculosis Conference in October 2008.

### ***Conclusions***

Although there is extensive quantitative research about TB, qualitative research is sparse, particularly related to HCW's attitudes and beliefs. Available evidence suggests that HCW's attitudes and beliefs about clients with TB are influential on client outcomes. Positive attitudes and beliefs are important to clients with TB and help increase client and their families' knowledge about TB and reduce stigma associated with TB.

The research study has identified the diversity of the HCW role and that staff attitudes are generally positive within the Auckland TB Control Team. Stigma surrounding TB remains a huge problem for clients, their families HCW and the wider community. There is no simple solution to address this stigma except to provide consistent, ongoing, accurate education. Immigration policy has created issues, within the TB arena and their policies need to be made clear. The issues of Public Health risk and client's rights also require clarification.

# Appendix 1

## *Participants Information Sheet*



Social and Community Health  
School of Population Health  
University of Auckland  
Private Bag, 92019, Auckland  
New Zealand

**Title: The Perceptions and beliefs of health care workers about Tuberculosis (TB).**

My name is **Jill Miller**. I am a student in Social and Community Health at the School of Population Health, University of Auckland conducting research in the Department of Community Health. I am conducting this research for my dissertation towards my **Masters of Public Health**. I have chosen this topic because I believe that **it will provide knowledge and understanding about perceptions and beliefs about Tuberculosis**.

You are invited to participate in my research and I would appreciate any assistance you can offer me. As part of my project I am conducting **Healthcare worker focus groups**. These groups will consist of three streams of disciplines, **medical staff, nursing and healthcare assistants** to explore their **perceptions of this issue**.

I would like to interview **you as part of a focus group**. You are under no obligation to be interviewed. Interview should take between **45 to 60 minutes** and would be during work time. I would prefer to audiotape the interview but this would only be done with your consent. The tape could be stopped at any part of the proceedings or you can withdraw information any time up until the 30<sup>th</sup> May 2006.

Following the completion of the interviews and analysis of the data a face to face Questionnaire will be developed and refined. Participants of the focus groups, who are willing, will be asked to complete this questionnaire with the researcher. This process will take between 30 to 45 minutes at a mutually suitable time.

If you wish to be interviewed please let me know by completing the enclosed Consent form and posting it to me or contact me by phone on TEL: **623 4600 ext: 27146** during work hours. All information you provide is confidential and your anonymity is guaranteed.

Thank you so much for your time and in making this study possible. If you have any questions or wish to know more about this study please do not hesitate to phone me at the number given or write to me at:

Jill Miller, Masters Student  
Social and Community Health  
The University of Auckland  
Private Bag 92019, Auckland.

My supervisor is:

Health

Professor David Thomas  
Social and Community Health, School of Population

The University Of Auckland  
Private Bag 92019  
Auckland.  
Phone: 09 373 7599 ext: 85657

The Head of the Department is:

as above

For any Queries regarding ethical concerns please contact:

***Jill Miller Cornwall Complex, Level 2, Building 15, Greenlane Clinical Centre.***

***Phone 623 4600 extension 27146.***

# Appendix 2

## Consent Form



Social and Community Health  
School of Population Health  
University of Auckland  
Private Bag, 92019, Auckland  
New Zealand

Title: The Perceptions and beliefs of health care workers about Tuberculosis (TB).

Researcher: Jill Miller

### REQUEST FOR INTERPRETER

#### Circle one

English	I wish to have an interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero.	Ae	Kao
Samoan	Ou te mana'o ia i ai se fa'amatala upu.	Io	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai

I have been given and understood an explanation of this research project.

I have had an opportunity to ask questions and have them answered.

I have been offered time to discuss my participation in the project with Whanau/ Family and /or a friend.

I understand that I may withdraw myself or any information traceable to me at any time up until 30<sup>th</sup> December 2006 without giving a reason.

- I agree/do not agree to take part in the research.
- I agree/do not agree that the interview will be audio taped.

Signed:  
Name:  
(Please print clearly).

**“This study has received ethical approval from the Northern Y Ethics Committee”**

# Appendix 3

## ***Guidelines for Focus Groups***

1. The Principal investigator will conduct all focus groups.
2. Focus groups will be semi-structured lasting approximately 30 to 60 minutes.
3. Participants will be put at ease and feel comfortable in the setting.
4. Participants will be assured of their anonymity and confidentiality.
5. All views of participants are relevant and valued. Natural conversation including new thoughts or ideas will be allowed and encouraged
6. All questions will be addressed to the entire group.
7. No individual participant will be singled out.
8. Diversity of comments and opinions will be encouraged amongst the group.

Considerable opportunity will be available within this framework for Health care workers to comment in detail on issues they consider most relevant and meaningful to their own experience.

## ***Questions for Focus Groups***

- What are your initial feelings when caring for Tuberculosis (TB) clients and their families?
- What are the main issues you encounter when you first become involved with TB clients?
- What other issues emerge for you during your contact with the client/family?
- How do you think client/family manage these issues?
- Are there any other comments that you would like to make about how TB impacts on clients/families/yourself?

## Appendix 4

**Table 4.1: Demographics for interviews**

### Characteristics of face to face interviews

Number	Location	Gender	Ethnicity	Age	Occupation
1	ARPH	Female	NZ/European	30	PHN
2	ARPH	Female	English	35	PHN
3	ARPH	Male	Other European	59	Doctor
4	ARPH	Female	Samoan	46	Health Assistant
5	ARPH	Female	Maori	45	Health Assistant
6	ARPH	Female	NZ/European	55	PHN
7	ACH	Female	English	60	RN
8	ACH	Female	NZ/European	50	RN
9	ACH	Male	NZ/European	60	Doctor
10	ACH	Male	NZ/European	35	Doctor

ARPH     Auckland Regional Public Health Service

ACH     Auckland City Hospital

RN     Registered Nurse

PHN     Public Health Nurse

# Appendix 5

## *Individual 'face to face' Questionnaire*

In your opinion and from your experience with TB clients and their families

1. What are the major impacts of TB diagnosis and treatment on the TB case?
2. What are the major impacts on the families of TB clients during hospitalisation of the case and through the process of contact tracing?
3. How does physical and social isolation affect clients and their families?
4. How do clients and their families cope with the impact of TB disease?
5. How does the stigma associated with TB affect clients and their families?
6. How does the stigma associated with TB affect you as a health worker?
7. In your opinion – in what ways can this stigma be overcome?
8. In what ways does the client's own cultural/spiritual belief system influence their acceptance of diagnosis and treatment?
9. What in your opinion are the main barriers to TB treatment and cure?
10. Would you like to comment on how these barriers could be overcome?
11. How do you think the wider community in NZ views the issue of TB
12. How do your friends and family view your work in the infectious disease specialty?
13. How important do you think – are the infection control precautions as part of your protection in the course of your work?
14. In what ways does Immigration policy influence the outcome of the diagnosis and treatment of TB in NZ?
15. Are there any other comments that you would like to make about your work with TB clients and their families – either in the hospital or in the community setting?

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